PARENTAL EXPERIENCES ON THE INCLUSION OF THEIR CHILD WITH DOWN SYNDROME IN A MAINSTREAM SCHOOL

By

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DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

.....	26 February 2021 .....
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ABSTRACT

Down syndrome, also known as Trisomy 21, is a genetic disorder that arises because of an additional chromosome due to abnormal cell division during fertilization (Sherman, Allen, Bean, & Freeman, 2007). Research has indicated that the prevalence of Down Syndrome in South Africa, is 1 in every 500 babies, and that Down Syndrome is the leading cause of intellectual impairment in children (Engelbrecht, Swart, & Eloff, 2001). Since the 1980's, research has established that children with Down syndrome who attend a mainstream school fair better academically and socially than their peers who attend special needs schools (Buckley, Bird, Sacks, & Archer, 2006; Engelbrecht, Swart, & Eloff, 2001; Hughes, 2006). However, limited research has been done towards understanding parents motivations for seeking inclusive learning environments for their child with Down syndrome, as well as their experiences of having their child mainstreamed.

The purpose of this study was to gain a deeper understanding of parents' experiences on the inclusion of their child with Down syndrome in a mainstream school. The study was conducted within an interpretive paradigm and followed a basic qualitative research design. Semi-structured interviews, field notes and reflective essay questions were used to collect data. The data was analysed through thematic content analysis to identify emerging themes from the data.

The findings of the study suggests that parents overall experience has been positive, however the cost of mainstreaming is expensive. Thus many parents of children with Down syndrome would not be able to mainstream their children within South Africa recommendations are made based on these findings.

SAMEVATTING

Down-sindroom, ook bekend as Trisomie 21, is 'n genetiese afwyking wat ontstaan as gevolg van abnormale seldeling tydens bevrugting (Sherman, Allen, Bean, & Freeman, 2007). Navorsing dui dat die voorkoms van babas wat gebore word met Down-sindroom in Suid-Afrika 1 uit elke 500 babas is, en dus word Down-sindroom as die hoofoorsaak van intellektuele gestremdheid by kinders geklassifiseer (Engelbrecht, Swart, & Eloff, 2001). Sedert die 1980's het navorsing vasgestel dat kinders met Down-sindroom wat 'n hoofstroomskool besoek, beter vaar akademies en sosiaal as hul eweknieë wat skole met spesiale behoeftes besoek (Buckley, Bird, Sacks, & Archer, 2006; Engelbrecht, Swart en Eloff, 2001; Hughes, 2006). Daar is egter beperkte navorsing gedoen om ouers se motiverings vir hoofstroomplasing en hul ervarings daarvan te bepaal.

Die doel van hierdie studie was om 'n dieper begrip te kry van ouers se ervarings oor die insluiting van hul kind met Down-sindroom in 'n hoofstroomskool. Die studie is binne 'n interpretatiewe paradigma uitgevoer en 'n basiese kwalitatiewe navorsingsontwerp was gevolg. Semi-gestruktureerde onderhoude, veldnotas en reflektiewe opstelvrae is gebruik om data in te samel. Die data is geanaliseer deur middel van tematiese inhouds analise om opkomende temas uit die data te identifiseer.

Die bevindings van die studie dui daarop dat ouers se algehele ervaring positief was, maar dat die koste van hoofstroom duur is. Dus sal baie Suid-Afrikaanse ouers van kinders met Down-sindroom nie hul kinders kan hoofstroom nie; op grond van hierdie bevindings word aanbevelings gemaak.

DEDICATION

I dedicate this thesis to my parents, Patrick and Bonita van den Eijnde, who chose to sacrifice greatly so that my sister and I can gain a tertiary education. We are eternally grateful and may this be a reminder to you of the legacy that you have built into our lives. We love you!

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TABLE OF CONTENTS

LIST OF TABLES

CHAPTER 1

INTRODUCTION TO THE STUDY

1.1 BACKGROUND TO THE STUDY

Inclusive education is based on the philosophy that all learners, regardless of any barrier to learning they may experience, has the right to be included within mainstream education. The history of South Africa shows that learners, especially those with disabilities, were excluded from mainstream education and were placed in special needs schools or special classes (Nel, 2018). However, global movements towards inclusion, in conjunction with the South African constitution and education policies, has provided a framework for inclusive education in South Africa (Eloff & Swart, 2018; Engelbrecht, Swart, & Eloff, 2001). South African schools, some faster than others, are moving away from exclusionary practices and embracing inclusive practices where the diverse needs of learners are addressed and accommodated (Swart & Pettipher, 2011). This has opened a gateway for learners with Down syndrome, and other children with disabilities, to attend mainstream schools.

Down syndrome, also known as Trisomy 21, is a chromosomal disorder where an individual has inherited an extra chromosome 21 due to incomplete cell division (Sherman, Allen, Bean, & Freeman, 2007). According to the statistics, 1 in every 500 babies born each year will be diagnosed with Down syndrome, making it the leading cause of intellectual impairment in South Africa (“Learn more”, 2017; Engelbrecht et al., 2001). The Diagnostic and Statistical Manual of Mental Disorders Fifth Edition, DSM 5, classifies Down syndrome as a neurodevelopmental disorder that manifests at birth and can produce developmental deficits in their personal, social, academic and occupational functioning (American Psychiatric Association, 2013).

Research over the last three decades, especially in the United Kingdom, established that learners with Down syndrome attending inclusive schools benefited more educationally than their counterparts who attended special needs schools (Hughes, 2006; Buckley, Bird, Sacks, & Archer, 2006). Studies show that learners with Down syndrome attending inclusive schools attained better expressive language, literacy and numeracy skills and had fewer behavioural difficulties (Buckley et al., 2006;

Engelbrecht et al., 2001; Hughes, 2006). Some studies also suggested that self-help and social skills attained by learners attending inclusive schools surpassed those of children attending special needs schools (Buckley et al., 2006).

1.2 STATEMENT OF THE PROBLEM

Research has established that learners with Down syndrome attending mainstream schools benefit more academically, as well as behaviourally, than their counterparts attending special need schools (Buckley et al., 2006). However, limited research has been done on how parents experience the inclusion of learners with Down syndrome within a mainstream school. According to Starr and Foy (2006, p. 316) a "number of studies have examined the perceptions and satisfaction of parents regarding the education of their children with developmental disabilities ranging in severity, but most have either not specified the nature of the disability of the children or have not anlysed the data by etiological classification". Starr and Foy (2006) also state that numerous studies have emphasised the need to investigate parents' perceptions of the education system that their child is enrolled in, from an etiological perspective, as it may vary depending on the child's diagnosis.

It has been said that the parental advocacy movement towards inclusion attributed a great deal towards the growth of inclusive education (Kasari, Freeman, Bauminger, & Alkin, 1999; Yssel, Engelbrecht, & Oswald, 2007) and that parents need to be considered essential collaborators, sharing the responsibility and decision making for outcomes in their child's education (Swart, Engelbrecht, Eloff, Pettipher, & Oswald, 2004), as they are at the heart of their children's lives, knowing their strengths and weaknesses most intimately (Kendall, 2017; Starr & Foy, 2006). Therefore, it is imperative that the lived experiences of parents are captured if we want to understand and support learners with Down syndrome within a mainstream school (Kendall, 2017).

1.3 PURPOSE

The purpose of this study was to gain a deeper understanding of parents' experiences on the inclusion of their child with Down syndrome in a mainstream school.

This was done in order to identify challenges that the learners and parents encounter within a mainstream school as well as to identify whether they receive adequate

support in order to address these challenges in the near future. Additionally, this study aimed at providing relevant information regarding inclusion to other parents with children who have Down syndrome so that they may be better informed before making decisions concerning their child's education.

1.4 RESEARCH QUESTION

The research question is:

> What are the lived experiences of parents on the inclusion of their child with Down Syndrom in a mainstream school?

The research question was guided by the following sub-questions:

1. What were the motivational factor/s behind the decision to enroll their child in a mainstream school vs a special needs school?
2. What are the challenges that are associated with the inclusion of learners with Down sydrome in a mainstream school?
3. What support was offered by the school for learners with Down syndrome?
4. Has the support offered by the school been adequate? And if not, what are the needs for support?
5. What benefits have been associated with enrolling your child in a mainstream school?

1.5 RESEARCH OBJECTIVES

The research question generates two objectives.

The primary objective was to identify themes on the lived experiences of parents on the inclusion of learners with Down syndrome within a mainstream school (Loebenstein, 2002).

Secondly, the study aimed to identify the challenges associated with the inclusion of learners with Down syndrome in a mainstream school with the purpose of addressing them in the near future.

1.7 RESEARCH DESIGN AND METHODOLOGY

1.7.1 Research Paradigm

A research paradigm is defined as a "model or pattern containing a set of legitimated assumptions and a design for collecting and interpreting data" (De Vos & Strydom, 2011, p. 40). In this study the aim was to gain a deeper understanding on the lived experiences of parents' on the inclusion of their child with Down syndrome within a mainstream school. According to De Vos et al. (2011) an interpretive paradigm aims to understand people and their lived experiences. An interpretive paradigm draws on the understanding that knowedge can be generated in many different ways and that knowledge or truth can mean different things to different people. Therefore to build knowledge on a phenomen, researchers should explore the meaning and perceptions people have within particular contexts. Thus, the study was conducted within an interpretive paradigm to allow the researcher to capture the individual lived experiences of parents (Thanh & Thanh, 2015). Transcripts, conversations, video tapes and field notes are often used within this paradigm in order to understand the real life context (De Vos, Strydom, Schulze, & Patel, 2011).

1.7.2 Research Design

According to Merriam (2002, p. 6) a basic qualitative design:

> *"… seeks to discover and understand a phenomenon, a process, the perspectives and worldviews of the people involved, or a combination of these."*

She also states that in this research design data is collected through interviews, observations, or document analysis to "identify recurring themes that cut across the data" (Merriam, 2002, p. 7). The researcher was seeking to understand and capture the lived experiences of parents on the inclusion of their child with Down syndrome within a mainstream school. Therefore, the researcher made use of a basic qualitative research design.

1.7.3 Research Participants

Four parents were purposively selected for this study. Purposive sampling is seen as a typical case sampling method in qualitative research (Strydom & Delport, 2011). It is also called judgemental sampling as the sample is selected based entirely on the researcher's descretion (Strydom & Delport, 2011).

In this study the researcher selected participants purposively based on two selection criteria. Firstly, participants were parents of children with Down syndrome who were enrolled in a mainstream school. Secondly, participants must have completed their formal basic education. This was required so that the researcher would be assured that participants had a full understanding of the research that would be conducted, as well as what would be expected of them if they chose to participate in this study. Participants who met these criterias were seen as rich sources of information who contain typical attributes that would serve the purpose of this study (Strydom & Delport, 2011).

1.7.4 Data collection methods

Data was collected through in-depth semi-structured interviews in conjuction with field notes and a reflective essay question.

1.7.4.1 Semi-structured interviews

Participants were required to participate in an in-depth interview guided by an interview guide. This was done to gain a detailed picture of the participants' lived experiences whilst the researcher and participants retained some flexibility during the interview process (Greef, 2011). According to Greef (2011) semi-structured interviews allow the researcher the opportunity to follow up on interesting avenues that emerge during the interview and allow the participants to paint a fuller picture. Semi-structured interviews are discussed in more detail in Chapter 3.

Due to the COVID-19 pandemic and the need to maintain social distancing, interviews were conducted online via Zoom. This allowed participants the freedom to participate in this study without placing them at risk of contracting the virus. A scheduled Zoom meeting protected with a username and password was set up by the researcher. Afterwards, the invitation to the meeting, with the specific link, was sent to the

respective participant via email or WhatsApp, depending on the participants preference. Thus, all that participants were required to do was to click on the link to join the meeting. Sessions were recorded and took approximately 45 minutes.

1.7.4.2 Fieldnotes

Fieldnotes are defined as a "written account of the things the researcher hears, sees, experiences and thinks about in the course of the interviewing" (Greef, 2011, p. 359). This allows the researcher to remember and explore the process of the interview afterwards (Greef, 2011). Therefore, fieldnotes were taken by the researcher during the interview sessions, followed by a written account after each session.

1.7.4.3 Reflective essay question

The Merriam-Webster dictionary define reflection as "a thought, idea, or opinion formed or a remark made as a result of meditation" (Merriam-Webster, 2019). Participants were asked to answer a reflective essay question about their experience on the inclusion of their child with Down syndrome within a mainstream school. This strategy was seen as appropriate by the researcher as it allowed for the gaining of more insight on their experience, so that the data would be richer, whilst complying with social distancing norms due to COVID-19.

1.7.5 Data analysis

Data was analysed through means of thematic content analysis. It has been said that thematic content analysis can be used "across a range of epistomologies and research questions" and that it is a "method for identifying, analyzing, organizing, describing and reporting themes found within a data set" (Nowell, Norris, White, & Moules, 2017, p. 2). Data analysis will be further discussed in Chapter 3.

1.7.6 Ethical Clearance and considerations

Firstly, ethical clearance from the University of Stellenbosch's Ethics Committee for Human Studies was sought to ensure that the correct procedures were in place. Then the consent of the participants who were purposively selected for this study was gained. Access to participants were gained as a result of personal connections made by the researcher and participants whilst providing educational support to learners with

Down syndrome within a mainstream school in Cape Town. Participants had already given their verbal consent that the researcher may contact them telephonically when ethical clearance had been provided. The researcher was no longer employed at the school,but she has however maintained good relationships with school personnel. Additionly, the researcher made provision for counselling support should any of the participants experience any emotional distress due to the nature of the study.

1.7.6.1 Informed consent

Informed consent is seen as one of the priniciples that is deemed necessary in ethical decision making. It is based on the researcher's respect for participants right to decide for themselves whether they are willing to participate in a study (Strydom, 2011). For participants to make an informed decision "the purpose of the study, the expected duration of the participants involvement, the procedure of the investigation, the possible advantages, disadvantages and dangers, as well as the credibility of the researcher must be provided to them" (Strydom, 2011, p. 117).

Thus, participants were contacted telephonically and invited to participate in the study. As previously mentioned, personal connections had previously been made thus the researcher already had access to the contact details of participants. During the telephone call the researcher explained the purpose of the study, what would be required of the participants, their right not to participate and to withdraw at any given moment during the process. Participants who were willing to participate in this study then received an informed consent form that was emailed to them to ensure that they were fully aware of what would be required of them and what their rights as participants are.

As a result of the COVID-19 pandemic participants were required to sign the consent form electronically via an application like Adobe. However, participants who were unable to do so were allowed to send the researcher a WhatsApp voicenote providing their consent to participate in this study.

1.7.6.2 Privacy

In any research study the privacy and identity of participants needs to be safeguarded to protect their attitudes, beliefs, opinions, experiences and behaviours (Strydom,

2011). In this study the researcher needed to know the names of the participants thus privacy had to be ensured to protect the identity and information that was provided during the data collection process. Therefore codes were assigned to the data during the collecting phase. After this data was anonymized by assigning pseudonyms to the data during the writing up process.

As previously mentioned interviews were conducted online via Zoom. Sessions were recorded so that the researcher could transcribe the data afterwards for analysis. Zoom records the audio as well as the visual components of a session. Thus, to protect the identity of the participants only the audio files were saved and stored in a secure, password protected file, on the researcher's computer. A backup of these files has been stored on the University's online storage platform OneDrive. The visual and playback files were deleted immediately from the researcher's computer after each session. The participants were made aware of this in the written informed consent form.

All written notes relating to this study has been locked in a secure filing cabanet at the researcher's house for five years.

1.7.6.3 Trustworthiness

According to Schurink, Fouchè, & De Vos (2011, p. 419) validity and reliability are seen as inappropriate constructs in qualitative research as they are unsuitable "in establishing the truth value". However, according to Merriam (2009, p. 209) validity and reliability in a qualitative research study can be ensured by conducting the investigation in an ethical manner. The following strategies for promoting validity and reliability in this study will be used namely: triangulation, an audit trail and researcher's reflexivity.

1.7.6.3.1 Triangulation

Triangulation refers to using "multiple investigators, sources of data, or data collection methods to confirm emerging findings" (Merriam, 2009, p. 229). In order to ensure triangulation different sources of data and data collection methods were used this study. Semi-structred interviews, fieldnotes and reflective essay questions were used to gather information.

1.7.6.3.2 Audit trail

According to Merriam (2009) an audit trail essentially refers to the detailed account of how the study will be conducted, thus referring to the methodology, and how data will be analysed. In this study a detailed account is presented in chapters 3 and 4.

1.7.6.3.3 Researcher's reflexivity

Merriam (2009, p. 219) states that researchers need to explain their biases, dispositions and assumptions with regards to the investigation that they are undertaking. Based on the researcher's experience on the inclusion of children with Down syndrome in a mainstream school, she did believe that the overall experience of parents would be positive. However, she believed that there had been challenges that parents had experienced. Thus, her motivation for this study was to highlight the positive aspects and the challenges that parents face with regards to inclusion, so that hopefully changes can be made to ensure that parents, and their children, reap more benefits from their inclusion into mainstream schools.

1.8 PRESENTATION OF THE RESEARCH

Chapter 1 introduces the study by describing the background of the research and providing an overview for the reader. The aim, purpose, and research questions are described in this chapter as well as an overview on topics that is discussed in more detail in the report.

The literature review in Chapter 2 presents relevant information regarding children with Down syndrome, inclusive education, and the inclusion of children with Down syndrome in a mainstream school. This was done in order to present a conceptual framework through which the findings of this study will be interpreted.

Chapter 3 describes the research design, methodology, and research methods used to collect data. The context of the research and research participants are also discussed.

Chapter 4 presents the findings of the research according to the themes that emerged during data analysis.

Chapter 5 presents the interpretation of the findings through the conceptual framework that has been described in Chapter 2. Recommendations for future research and limitations are discussed at the end of the chapter.

1.9 DEFINITIONS OF TERMS

1.9.1 Down syndrome

Down syndrome is a chromosomal disorder that arises due to the addition of an extra chromosome 21 that occurs as a result of incomplete cell division (Sherman, Allen, Bean, & Freeman, 2007).For the purpose of this study the term Down syndrome includes all children who have been diagnosed with this disorder as the cause of the disorder has little effect on the barriers to learning experienced by these children (Down Syndrome South Africa, 2013). The causes of Down syndrome are discussed in more detail in Chapter 2.

1.9.2 Mainstreaming

Mainstreaming refers to the “returning of learners with disabilities to the mainstream of education” (Swart & Pettipher, 2011, p. 7) as far as is reasonably possible, to learn alongside their neurotypical developing peers for part of the day (Alquraini & Gut, 2012).

1.9.3 Integration

According to Swart & Pettipher, (2011, p. 8) integration refers to “the democratic right of every child to public education” and “aims to maximise the social interactions between the ‘disabled’ and ‘non-disabled’”.

1.9.4 Full inclusion

Full inclusion implies that “all students, regardless of handicapping condition or severity, will be in a regular classroom/program” on a full time basis (Anastasiou, Kauffman, & Di Nuovo, 2015, p. 430). Furthermore it implies that “all services must be taken to the child in that setting” (Anastasiou et al., 2015, p. 430) instead of the child being taken out of the setting to receive specialized services.

1.10 CONCLUSION

In this chapter the researcher provided the reader with the background to the study, how the research was conducted and what can be expected in the rest of the report. Within this chapter the motivation for the study, research questions, the research paradigm, methodology, research methods and data ananlysis was discussed.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The researcher's aim of this chapter is to provide the most relevant information on the inclusion of children with Down syndrome. The chapter starts with providing a conceptual backdrop explaining the concepts of inclusion and inclusive education. Thereafter, the researcher discusses the influence of international policies and conventions on South Africa's policies and legislation regarding inclusive education.

After this, Down syndrome as a condition will be discussed. The researcher will then review the effects of mainstreaming and lastly at parents' perceptions on the inclusion of children with Down syndrome in mainstream schools.

2.2 INCLUSION

As previously stated, the proposed purpose of this study was to gain a deeper understanding of parents' lived experiences on the inclusion of their child with Down syndrome within a mainstream school. Therefore, it is important that the concept of inclusion and inclusive education is explored in-depth to understand and make meaning of parents' lived experiences.

According to Swart and Pettipher (2011), the concept of inclusion is quite complex as it has come to mean different things to different people. However, there are some broad principles guiding the concept of inclusion, for example, "a dedication to building a more democratic society, a more equitable and quality education system, and a belief that extends the responsibility of regular schools to accommodate the diverse learning needs of all learners" (Swart & Pettipher, 2011, p. 4). Thus, in a broader sense the concept of inclusion focuses on the development of more inclusive communities and education systems. Therefore, it is based "on a value system that invites and celebrates difference and diversity arising from gender, nationality, race, language, socio-economic background, cultural origin and level of educational achievement and disability" (Swart & Pettipher, 2011, p. 4).

According to Mugambi (2017, p. 93) inclusive education is the “process of strengthening the capacity of the education system to reach out to all learners as a strategy to achieve education for all”. Inclusive education is based on the belief that education is a basic human right for all as established by The Universal Declaration of Human Rights in 1948 (Mugambi, 2017). According to Nel (2018), there appears to be two leading viewpoints on inclusive education. The first viewpoint focuses on the inclusion of learners with disabilities in mainstream schools, whereas the second viewpoint emphasises that inclusion is about accommodating diverse learning needs, not only those with disabilities. Although the researcher agrees that all learners facing barriers to learning should be the focus of inclusive movements, it cannot be denied that learners with disabilities continue to be the most vulnerable to being excluded by mainstream schools (Nel, 2018).

Several international conventions and conferences advocated and presented frameworks with regards to inclusive education, however, some played a more integral role in advocating the rights of learners with disabilities. At the United Nations Convention on the Rights of the Child in 1990, it was stated that children with or without disabilities have the same rights to educational opportunities and that governments need to ensure that children with disabilities have access to education (Mugambi, 2017). According to Nel (2018) at the World Declaration on Education for All Conference in 1990, a Framework for Action to Meet Basic Learning Needs was presented and adopted by 155 countries. During this conference, it was advocated that children in every category of disability should have equal access to education (Nel, 2018, p. 260). However, it was at the World Conference on Special Needs Education in Salamanca, Spain, that great strides were made to “endorse inclusive education” when the Salamanca Statement and Framework for Action on Special Needs was “adopted and signed by 92 countries, including South Africa” (Nel, 2018, p. 260). This framework states that “every child has a fundamental right to education and must be given the opportunity to achieve and maintain an acceptable level of learning” and that “schools should accommodate all children regardless of their physical, intellectual, social, emotional, linguistic or other conditions” (UNESCO, 1994, p. viii). This framework emphasised the need to accommodate and grant access to children with disabilities into mainstream schools where they are allowed to learn alongside their peers whilst additional support is provided to address learning needs as they arise

(Nel, 2018). It provided a gateway for learners with disabilities to attend mainstream schools within their communities.

Within South Africa, the Education White Paper 6 on special education, building an inclusive education and training system (Department of Education, 2001) provides a framework for inclusive education within our unique context and is guided by the following principles: “human rights and social justice for *all* learners; participation and social integration; equal access to a single, inclusive setting; access to the curriculum; equity and redress; community responsiveness; and cost-effectiveness” (Department of Education, 2001, p. 5). This framework provides a strategy and implementation plan that stretches over a 20 year period to transform South Africa’s education system into an inclusive education system to redress past injustices within our country (Nel, 2018; Department of Education, 2001). Based on the above-mentioned conventions, conferences and frameworks presented children with disabilities have the right to attend a mainstream school within their communities, receive a quality education that is meaningful to them (Mugambi, 2017), and support as the need arises, which includes children with Down syndrome.

2.3 INCLUSIVE EDUCATION

2.3.1 Global conversations on Inclusive Education

Global conventions and discourses on inclusive education have provided a framework for the implementation of inclusive education within South Africa.

Education has been accepted as a basic human right globally since the Universal Declaration of Human Rights (UDHR) in 1948 just after the 2nd World War (Nel, 2018). Since then numerous conferences and conventions have affirmed this basic human right, but it was only in 1990 in Jomtien, Thailand, at the World Declaration on Education for All that the Framework for Action to Meet Basic Learning Needs that specific attention was given to the movement and implementation of inclusive education (Nel, 2018). During this conference, 1500 delegates representing 155 governments worldwide gathered at Jomtien to discuss the major aspects of Education for All. The purpose of this conference was to impress a renewed commitment to the worldwide drive to provide universal primary education to all and eliminate adult

illiteracy, whilst providing strategies to inspire governments to improve the basic quality of education and finding cost-effective ways to meet the basic learning needs of disadvantaged populations in an effort to rectify disparities amongst these groups (UNESCO, 1990). Children with disabilities were amongst the disadvantaged populations identified at Jomtien and it was documented that procedures need to be put in place to provide equal access to education to every category of disabled persons (UNESCO, 1990).

However, it was only in 1994 at the World Conference on Special Needs Education in Salamanca, Spain that great strides were made to endorse inclusive education when 92 countries (including South Africa) adopted the Salamanca Statement and Framework for Action on Special Needs Education (SSFASNE) (Nel, 2018). The cornerstone of this framework that guides the endorsement of inclusive education is the belief that "schools should accommodate all children, regardless of their physical, intellectual, social, emotional, linguistic or other conditions" (UNESCO, 1994, p. 6) thus providing a gateway for children with Down syndrome to enter mainstream schools. The framework also states that "all children should learn together, wherever possible, regardless of any difficulties or differences they may have" (UNESCO, 1994, p. 11) and that special schools or classrooms should be the exception and only recommended in those infrequent cases in which the general education classroom isn't able to meet a child's educational or social needs or the child's welfare, or others, will be placed at risk (UNESCO, 1994). According to the SSFASNE:

> *"Inclusive schools must recognize and respond to the diverse needs of their students, accommodating both different styles and rates of learning and ensuring quality education to all through appropriate curricula, organizational arrangements, teaching strategies, resource use, and partnerships with their communities. There should be a continuum of support and services to match the continuum of special needs encountered in every school (UNESCO, 1994, pp. 11-12).*

According to Nel (2018), the SSFASNE provided a foundational narrative of how inclusive education is to be understood globally.

The Dakar Framework for Action: “Education for All: Meeting our collective commitments” adopted in Senegal in 2000 re-affirmed the vision of EFA set out in Jomtien, Thailand in 1990 (UNESCO, 2000). This framework explicitly expresses the global commitment to “pursue a board-based strategy for ensuring that the basic learning needs of every child, youth and adult are met within a generation and sustained thereafter” (UNESCO, 2000, p. 12). Although the framework does not specifically focus on learners with special needs or disabilities it does state the importance of expanding and improving comprehensive early childhood care and education, especially for the most vulnerable and disadvantaged children. This can be done by developing and introducing programmes that focus on a child’s development holistically. These programmes should include health, nutrition, hygiene, cognitive and psycho-social development and should be presented in a child’s mother tongue as well as help identify and enrich the care and education received by special needs children (UNESCO, 2000).

The Convention on the Rights of People with Disabilities (CRPD) is an international human rights treaty of the United Nations adopted in 2006 and ratified by South Africa in 2007 (United Nations, 2006; Nel, 2018). It was designed to:

> *“promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and promote respect for their inherent dignity” (United Nations, 2006, p. 3).*

According to the CRPD state parties should ensure that persons with disabilities (whether physical, mental, intellectual, or sensory) can access inclusive, quality, and free primary as well as secondary education on an equal basis as their peers. In addition, they should receive adequate support within the general education system and provide effective individual support measures that maximize academic and social development which is consistent with the goals of full inclusion (United Nations, 2006).

2.3.2 Inclusive Education in South Africa

The international policies on inclusive education and the Constitution of South Africa post 1994 has provided the framework and guidance for inclusive education within South Africa (Engelbrecht, Nel, Smit, & van Deventer, 2016). South Africa has a unique heritage and with that a unique set of challenges due to our history of laws which

overlooked the human rights of certain population groups (Nel, 2018). In the previous regime, that is the years prior to 1994, referred to as *apartheid*,[1] discriminatory policies and practices often segregated learners based on disabilities and along racial lines. Black learners attended separate schools than white learners and these schools were often under resourced and ill-equipped to accommodate learners with disabilities. Most learners with disabilities were placed in well-resourced special schools or classrooms which mostly accommodated white learners (Nel, 2018). According to Nel (2018), only a few under-resourced special schools were available for black learners nationwide, and thus, as a result, many were mainstreamed due to the lack of availability.

The new Constitution of South Africa, post 1994, states in that every individual, regardless of their race, gender, ethnicity, disability, or language has the right to a basic education (Republic of South Africa: Constitution of the Republic of South Africa, 1996). This is further emphasised by the South African Schools Act of 1996 that provides for the provision of a basic education for all South Africans (Republic of South Africa: South African Schools Act, 1996) . Section 5(1) of the Act states that “a public school must admit learners and serve their educational requirements without unfairly discriminating in any way” (Republic of South Africa: South African Schools Act, 1996). The Act also further states that learners with special educational needs, need to be admitted to an ordinary school, where it is reasonably practicable, and that the relevant educational support needs to be provided. This includes “adaptive and supportive measures of assessment to ensure they have equal opportunities to demonstrate their level of attainment” (Republic of South Africa: South African Schools Act, 1996). Thus, based on the South African Constitution as well as the South African Schools Act children with Down syndrome have the right to a basic education; to be mainstreamed where it is reasonably practicable in addition to receiving the relevant educational support they require from the school.

According to Engelbrecht et al. (2016) Education White Paper 1 (EWP 1) on Education and Training (1995) and the South African Schools Act provided a basis that facilitated a paradigm shift in the views of learning needs and disability. In addition, the White Paper on an Integrated National Disability Strategy published in 1997 advocates that

[1] *Apartheid is defined as “a political system in which people of different races are separated* (Cambridge Dictionary, 2021).

learners with disabilities must be granted full access into the inclusive and training system and that equity will be obtained through the provision of educational support services (Down Syndrome South Africa, 2013). On the other hand, the Education White Paper 5 on Early Childhood Education (EWP 5) published in 2001 addresses the unsatisfactory educational experiences that learners with disabilities have received and states that these learners are largely not catered for in mainstream ECD programs despite the critical age for early intervention (Department of Education, 2001). However, the policy that is seen as fundamental in all educational decisions and practices within South Africa is the Education White Paper 6 on Special Needs Education: Building an Inclusive Education and Training System (EWP 6) (Nel, 2018).

The EWP 6 published by the Department of Education in July 2001 provides a policy framework to meet the diverse needs of learners within the schooling system. The policy was developed as a response to address the past injustices experienced by learners with special educational needs. According to the EWP 6 only a small percentage of learners with disabilities, mainly white learners, received specialised education and support during *apartheid*, thus many were either mainstreamed by default or were kept at home. In 2001, seven years after the country become a democratic country, it was estimated that about 280 000 learners with disabilities were not attending school, thus one of the driving factors of the policy change was to address this by developing an inclusive education and training system that allow learners with disabilities the opportunity to develop to their fullest potential alongside their peers were reasonably practicable. According to the EWP 6 “, the National Disability Strategy condemns the segregation of persons with disabilities from the mainstream of society” (Department of Education, 2001, p. 10).

In the EWP 6, the term “learners experiencing barriers to learning and development” or more commonly known as barriers to learning was introduced (Department of Education, 2001). This was done due to the negative connotations made with previous terms used like “learners with special educational needs” as these terms often led to the labelling and stigmatization of learners which led to exclusion (Nel, 2018). Also, often these terms only addressed organic causes or factors within the learners and didn’t address factors outside of the learner that resulted in poor academic performance or difficulties experienced at school. A barrier to learning is anything that

inhibits a child to learn, and the cause can either result from within the learner or from outside the learner. According to the EWP, 6 intrinsic factors are those that arise from within the learner and have organic causes such as: “physical, mental, sensory, neurological and developmental impairments, psycho-social disturbances, differences in intellectual ability, particular life experiences or socio-economic deprivation” (Department of Education, 2001, p. 7). As Down syndrome is a neurological disorder with an organic cause it will be classified as an intrinsic factor according to the EWP 6. Extrinsic factors on the other hand are factors that are outside of the learner which can result in the learner experiencing a learning difficulty such as: “negative attitudes to stereotyping of difference, an inflexible curriculum, inappropriate languages or language of learning and teaching, inappropriate communication, inaccessible and unsafe built environments, inappropriate and inadequate support services, inadequate policies and legislation, the non-recognition and non-involvement of parents, and the inadequate and inappropriately trained education managers and educators” (Department of Education, 2001, p. 7).

In addition to this, the policy categorizes schools into three categories namely: ordinary schools, full-service schools, and special schools. Each category of schools is equipped to provide a certain level of support to its learners. Ordinary schools are equipped to cater for learners who experience mild disabilities or barriers to learning, whilst full-service schools are equipped to provide educational support to learners who experience moderate disabilities or barriers to learning. Special schools are included within the EWP 6 education and training system and they are equipped to cater for learners who require a high or intensive level of support and serve as resource centres for full-service and ordinary schools. It also states that learners needs to be placed into a specific school based on the level of support required by the learner to succeed, which makes provision for learners with Down syndrome who experience mild or moderate disabilities to attend either ordinary or full-service schools within their district (Department of Education, 2001).

2.4 DOWN SYNDROME

2.4.1 What is Down syndrome?

John Langdon Down was the first person to describe Down syndrome in 1866 (Sherman et al., 2007; Lorenz, 1998). Down was a physician at Earlswood Asylum for Idiots, in England. There he discovered a group of individuals who could be distinguished from other individuals who were intellectually disabled. These individuals were short in stature and had specific characteristics namely: oblique eye fissures, epicanthal folds, flat nasal bridge, and a protruding tongue (Sherman et al., 2007). However, it was only in 1959 that the genetic basis of Down syndrome was discovered by Professor Jerome Lejeune in Paris (Lorenz, 1998).

Down syndrome, also known as Trisomy 21, is a chromosomal disorder that arises due to the inheritance of an extra chromosome 21 (Down Syndrome South Africa, 2013). Each cell in our bodies has a nucleus that contains all our genetic material in the form of chromosomes. Generally, a person has a total of 46 chromosomes or 23 chromosome pairs. We inherit 23 chromosomes from our father and 23 chromosomes from our mother. In the case of Down syndrome an additional chromosome 21 or in some cases a part of chromosome 21 is inherited due to incomplete cell division (Sherman et al., 2007). Ninety to ninety-five percent of babies born with Down syndrome is due to a process called meiotic nondisjunction which results in standard Trisomy 21, which means that every cell in a person's body contains an additional chromosome 21 (Down Syndrome South Africa, 2013; Sherman et al., 2007). However, in 1-2 percent of babies born with Down syndrome, only some cells contain an additional chromosome 21 due to somatic mosaicism which results in mosaic Trisomy 21, the remainder of cases are due to chromosome 21 translocations (Sherman et al., 2007; Down Syndrome South Africa, 2013). Despite the cause of incomplete cell division, whether due to meiotic nondisjunction, somatic mosaicism, or translocations, the effects of an additional chromosome are likely to be similar.

Research has shown that children with Down syndrome follow the same developmental stages as their neurotypically developing peers (Down Syndrome South Africa, 2013). The difference is that children with Down syndrome will reach their developmental stages later and stay there for longer before reaching the following

developmental stage. Their development is also continual throughout life although it can be an unsteady process (Down Syndrome South Africa, 2013). Research has also established that although all children with Down syndrome will experience learning difficulties, these difficulties are on a continuum ranging from mild to severe (Down Syndrome South Africa, 2013). As a result of this finding children with Down syndrome can enter mainstream education based on the severity of their learning difficulties, and the level of support needed.

2.4.2 Learners with Down syndrome in mainstream schooling

Prior to the 1980's, it was believed that children with Down syndrome were not able to learn how to read, due to their "limited" mental capacity (Buckley & Bird, 1993), however in 1979 a letter addressed to an educational psychologist in Portsmouth, England lead to a rather interesting new discovery.

In 1979 a father, Leslie Duffen, wrote a letter describing how his daughter, Sarah, who has Down syndrome learnt how to read at the age of three (Buckley & Bird, 1993). He stated that he taught Sarah with the use of flashcards. According to the researchers (Buckley & Bird, 1993), he would write the words he wanted her to learn on the flashcards and observed that she learnt the written words at a faster rate than words she only experienced audibly. When the father wrote the letter, Sarah was 12 years old and in mainstream schooling (Buckley & Bird, 1993). He believed that other children with Down syndrome could also benefit in the same way as Sarah did and that it could be a "way-in" to language with these children (Buckley & Bird, 1993).

Thus, in 1980, a study was launched to investigate the reading ability of children with Down syndrome at an early age. For the study, fifteen pre-school children with Down syndrome were selected and their progress was tracked for three years. These children received a regular home-teaching program from the researchers, through a teacher whom they employed to implement the program (Buckley & Bird, 1993).

The findings in this study were quite insightful and revolutionary challenging the belief (s) held about the cognitive capabilities of children with Down syndrome. Based on the researchers' findings the study concluded that children with Down syndrome have the ability to learn how to read at an early age and that it was a "way in" to language development (Buckley & Bird, 1993). Some of the observations that led to this

conclusion were as follows. The researchers found that the children were making semantic errors when reading the flash cards. In other words they would say a different word that meant the same as the word on the flash card. Based on this finding the researchers concluded that the children were decoding the written word for meaning and not just “barking at print” (Buckley & Bird, 1993, p. 35). This ability was again emphasised when these children were able to use sign language to indicate the correct response to the word on the flashcard. The researchers also observed that the children were able to sign the correct response quicker, than saying it verbally. This implied that the language speech delay typically experienced by children with Down syndrome cannot be attributed entirely to the general cognitive delay, and it meant that they are more intelligent and have more understanding than what was previously believed. (Buckley & Bird, 1993) This study impacted the inclusive education policy in England and provided a gateway for children with Down syndrome to enter mainstream education.

Since then, several studies have compared the outcomes of children with Down syndrome attending mainstream versus special needs schools. Four decades of research has indicated that children with Down syndrome can be mainstreamed successfully and that children with Down syndrome who attend mainstream schools excel academically and, according to some, socially compared to their counterparts who attend special needs schools (Buckley et al., 2006; Hughes, 2006; Lorenz, 1999; Laws, Byme, & Buckley, 2000; Engelbrecht et al., 2001).

Research done by Sloper et al. (1990 cited in Laws et al., 2000) and Beadman (1997) (cited in Laws et al., 2000), indicated a strong correlation between the type of school attended, mainstream versus special needs, and academic attainments with regards to reading, numeracy, and writing skills. According to Laws et al. (2000), these educational advantages could be due to the fact that children who attend mainstream schools have more exposure to “normal” language and more focus is placed on literacy and numeracy instruction than in special needs schools. Laws et al. (2000) investigated the effect that school placement has on the language and memory development of children with Down syndrome and found that children who were mainstreamed scored higher on vocabulary, grammar, and digit span measures, but not on non-language based memory measures.

Another study comparing the outcomes of teenagers with Down syndrome attending mainstream schools versus special needs schools found that teenagers who attended a mainstream schools expressive language was 2 years and 6 months ahead of those who attended special needs schools (Buckley et al., 2006). The study also found that the teenagers who attended mainstream schools were 3 years ahead in receptive language, reading as well as writing skills, however, they also stated that the teenagers who had attended special needs schools were more likely to have a special “girlfriend” or “boyfriend”. Despite this, the researchers stated that the teenagers who were mainstreamed were more socially mature demonstrating social behaviour that was more age-appropriate and having more social inclusion gains (Buckley et al., 2006). Hughes (2006) also emphasises these observations stating that children with Down syndrome who are fully included in mainstream classes show gains in spoken language, reading, writing, numeracy, general knowledge as well as social independence.

2.4.3 Parental reflections on mainstreaming their child with Down syndrome

The parental advocacy movement toward inclusion is attributed in part towards inclusive education (Kasari et al., 1999; Yssel et al., 2007). Research has stated that parents need to be considered essential collaborators in their child’s education as they are at the heart of their children’s lives, knowing their strengths and weaknesses most intimately (Kendall, 2017; Starr & Foy, 2006). This notion is also recognized in international and national policies such as the South African Schools Act 1996 and the Education White Paper 6, which according to Engelbrecht et al. (2007), has empowered parents to become strong advocates for the inclusive education movement.

According to Starr and Foy (2006) numerous studies have investigated parental perceptions and satisfaction regarding the education of their child with developmental disabilities, however, the nature of the disability experienced was not specified nor was the data analysed by etiological classification. It seems evident from the literature that parents of children with Down syndrome prefer that their child attends an inclusive educational setting (Hodapp et al., 1998; Kasari et al, 1999; Starr & Foy, 2006). It appears that “having a knowledgeable and supportive staff, feeling a part of the decision-making concerning their child, and having teachers who are willing to learn

about the disability and make appropraite adaptions are among the contributing factors to their satisfaction" (Starr & Foy, 2006, p. 331) irrespective of the nature of the disability experienced by their child, makes parents feel at ease and confident that there child is happy.

Starr and Foy (2006) go on to state that studies have emphasised the need for researchers to investigate parents' perceptions on school placement from an etiological perspective as it may vary depending on a child's diagnosis. Hodapp et al. (1998) (as cited in, Starr & Foy, 2006) stated that in their investigation that parents of Down syndrome children felt that an inclusive setting is the more ideal educational setting. This same perception was reported by Kasari et al. (1999) with 75% of parents demonstrating positive attitudes towards inclusion.

A recent study done by Kendall (2017) investigated parents' perceptions of the support provided in mainstream education for their children with Down syndrome in England. The findings show that parents viewed a positive attitude from staff towards their child and inclusive practices as paramount for successful inclusion. In addition, parents viewed the willingness of education staff to work in partnership with them, especially during the transitions from educational phases as critical. Parents also reported the accessibility and funding of support services, such as speech and language therapy, as factors that are important for successful inclusion.

2.5 CONCLUSION

The literature review provides a backdrop for understanding the concepts of inclusion and inclusive education. It then goes on to inform readers on the rights of children with Down syndrome as it pertains to mainstream education. The review then goes on to provide the effects that school placement has on children with Down syndrome and lastly looks at parents' perceptions on the inclusion of their child with Down syndrome.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

As mentioned in Chapter 1 the study investigated parents' experiences on the inclusion of their child with Down syndrome in mainstream school. This chapter aims to elaborate on the research process and all the considerations that were undertaken to gather and analyse the findings.

3.2 RESEARCH PARADIGM AND DESIGN

The following section explains the purpose of the study, the research paradigm, and the research design of the research.

3.2.1 Purpose of research and research questions

Before engaging in the research design and methodology it is of great importance that we relook at the purpose as well as the research questions that guided this study. Both of these aspects informed the researcher on the research process and design that was implemented. As stated in Chapter 1, the purpose of this study was to gain a deeper understanding of parents' experiences on the inclusion of their child with Down syndrome in a mainstream school. The study was guided by the following research questions.

The main research question was:

> *What are the lived experiences of parents on the inclusion of their child with Down syndrome in a mainstream school?*

The sub-questions that guided the research question was:

1. What were the motivational factor/s behind the decision to enrol their child in a mainstream school vs a special needs school?
2. What are the challenges that are associated with the inclusion of learners with Down syndrome in a mainstream school?

3. What support was offered by the school for learners with Down syndrome?
4. Has the support offered by the school been adequate? And if not, what are the needs for support?
5. What benefits have been associated with enrolling your child in a mainstream school?

3.2.2 Research paradigm

The term paradigm originated in the natural sciences and was first introduced by the author Thomas Kuhn (De Vos & Strydom, 2011). Despite its origin, it has played a major role in the “philosophy and methodology of the social sciences” (De Vos & Strydom, 2011, p. 41). It has been said that various scholars have understood the term differently (Thanh & Thanh, 2015).

According to Bogdan and Biklen (as cited in Mackenzie & Knipe, 2006, p. 3) a paradigm is a “loose collection of logically related assumptions, concepts, or propositions that orient thinking and research” whereas Cohen and Manion (as cited in Mackenzie & Knipe, 2006, p. 3) defines it as a “philosophical intent or motivation for undertaking a study”. Babbie (2010, p. 33) states that paradigms are “the fundamental models or frames of reference we use to organize our observations and reasoning”. Despite these different definitions and interpretations of the term, commonalities can be made in one’s understanding of the word. It is clear that a paradigm is a way of viewing one’s research (Babbie, 2010; De Vos & Strydom, 2011) and impacts the type of research conducted as well as the methodologies used. This same notion or idea is emphasised by Mackenzie and Knipe (2006, p. 2) that states that the choice of paradigm “sets down the intent, motivation, and expectations for the research”. They go on to state that “ without nominating a paradigm as the first step, there is no basis for subsequent choices regarding methodology, methods, literature or research design” (Mackenzie & Knipe, 2006, p. 2). In this study the researcher was seeking to gain a deeper understanding of parents’ lived experiences on the inclusion of their child with Down syndrome in a mainstream school to identify emerging themes and challenges that arise due to inclusion, thus an interpretive paradigm was chosen.

3.2.2.1 Ontology

Ontology is defined as the “nature of reality” (Merriam, 2009, p. 8). According to research the core belief of the interpretivst paradigm is that reality is socially constructed (Thanh & Thanh, 2015; Mackenzie & Knipe, 2006) and that “multiple realities, or interpretations, of a single event”, exists (Merriam, 2009, p. 8). Thus within an interpretivist paradigm researchers rely heavily upon the perceptions and views of the participants on the subject matter being investigated (Creswell, 2014). During the research process of this study, four parents’ shared their perspectives on the inclusion of their child based on their own lived experiences. Although commonalities between participants’ views did emerge, differences were also noted.

3.2.2.2 Epistemology

Epistemology refers to the “nature of knowledge” (Merriam, 2009, p. 8). Within an interpretive paradigm, it is believed that knowledge is constructed (Merriam, 2009), through the interpretation of data. Thus multiple perspectives need to be included, making it more inclusive and leading to a more comprehensive understanding of the subject matter being investigated (Thanh & Thanh, 2015). Within this paradigm, the researcher also recognizes that “their own backgrounds shape their interpretation” and thus “they position themselves in the research to acknowledge how their interpretation flows from their personal, cultural, and historical experiences” (Creswell, 2014, p. 8). To position herself within the research the researcher did a literature review of the subject matter and used that, in addition to her own experience, to link with the knowledge and understanding gained through the participants’ experiences.

3.2.2.3 Methodology

The purpose of this study was to gain a deeper understanding of parents’ experiences on the inclusion of their child with Down syndrome within a mainstream school. Thus a qualitative research methodology was followed as interpretive research is often supported by this methodology (Merriam, 2009). Qualitative research can be seen as “an umbrella term covering an array of interpretive techniques” that allow the researcher to “describe, decode, translate,” and make meaning of “ naturally occurring phenomena in the social world” (Van Maanen, 1979, p. 520). One of the goals of qualitative research is to understand and make meaning of people’s experiences within

the world (Merriam, 2009). Denzin and Lincoln (2015, p. 3) states that fieldnotes, interviews, conversations, photographs, recordings, and memos are all methods used within natural settings (Creswell, 2014) to draw meanings from. The process is inductive in nature as the researcher uses the data gathered to build concepts or identify emerging themes that cut across all the data (Creswell, 2014; Merriam, 2009). The researcher is seen as the primary instrument as he or she is responsible for collecting and analyzing the data (Creswell, 2014; Merriam, 2009).

3.2.3 Research design

According to Monette et al. (2008, p. 9), a research design can be defined as a "plan outlining how observations will be made and how the researcher will carry out the project". Thus it is clear from this definition that the purpose of the research design is to provide a specific direction informing the researcher on the procedures required to follow (Creswell, 2014). The research design can be seen as a step within the research process that follows the "problem formulation and precedes data collection" (Fouchè, Delport, & De Vos, 2011, p. 143). For the purpose of this study, the researcher decided to use a basic qualitative research design as the study sought to understand the lived experiences of parents of children with Down syndrome who are enrolled in a mainstream school. As previously stated Merriam (2002, p. 6) define a basic qualitative design as one that

> *"… seeks to discover and understand a phenomenon, a process, the perspectives and worldviews of the people involved, or a combination of these."*

She goes on to state that in qualitative research this design is the most commonly found within the education sector. Interviews, observations, and document analysis are all methods used within this design to gather data (Merriam, 2009). Data is then analysed to identify recurring patterns or themes that emerge from all the data gathered. It is important to note that within this design the interpretations of results will be based on the researcher's understanding of the participants' understanding regarding the subject matter being investigated (Merriam, 2009). Thus the primary purpose of this study following a basic qualitative research design is to uncover and

interpret the meanings of parents' experiences on the inclusion of their child with Down syndrome within a mainstream school.

3.3.4 Context of the research

Within a qualitative study, the social context in which the study is conducted is important to understand. If it is not correctly understood it can alter the meanings and social significance of a study (Neuman, 2014). The study is investigating parents' experiences on the inclusion of their child with Down syndrome in a mainstream school. The pupils' parents' that were interviewed all attended one of two private mainstream schools in the Cape metro in the Western Cape. Both of these schools are registered at the Western Cape Education Department as independent schools. The first school is an inclusive pre-primary school that includes children with Down syndrome and operates at a twenty percent Down syndrome and eighty percent mainstream ratio. Each class has a maximum of fifteen pupils and has a qualified teacher and facilitator per class and follows the CAPS curriculum. Whereas the second school is primary as well as a high school. It follows the Accelerated Christian Education curriculum that allows its pupils to work at their own individual pace.

3.2.5 The role of the researcher

One of the unique characteristics of qualitative research is the role of the researcher. According to Creswell (2014), the researcher has multiple roles and responsibilities that start at the stage of conceptualization through to the implementation of completion of the study. Many of these roles are fulfilled subconsciously, whilst others are conducted consciously. One of these roles is the researcher as the primary instrument for data collection and analysis (Merriam, 2009). Within this study the researcher, was the primary instrument of data collection, transcription, and analysis. This allowed me, the researcher, to be constantly emerged within the process and made it possible to respond immediately and adapt questions during the interview process as more themes started to emerge during the data collection process. The researcher remained objective throughout the process by reviewing the findings with her supervisor and practicing reflexivity to ensure that her own biases or opinions would not impact the interpretations and conclusions made in this study (Creswell, 2014; Merriam, 2009). The researcher's reflexivity is further discussed in detail later in the chapter.

3.2.6 Research participants

The goal of qualitative research is to understand and make meaning of peoples' lived experiences (Merriam, 2009) and the purpose of this study was to gain a deeper understanding of parents' experiences on the inclusion of their child with Down syndrome in a mainstream school. Thus within this study, the researcher made use of purposeful sampling, also called purposive or judgemental sampling as it relies entirely on the researcher's discretion, to identify potential participants (Merriam, 2009; Strydom & Delport, 2011). According to Patton (2002, p. 46), the "logic and power of purposeful sampling derive from the emphasis on in-depth understanding", thus requiring the researcher to select participants that can be viewed as information-rich cases. Patton describes an information-rich case as someone whom "one can learn a great deal" from regarding the issue or issues of "central importance to the purpose" of the study (Patton, 2002, p. 46). Thus with purposeful sampling pre-selected criteria for the selection of participants is of utmost importance (Strydom & Delport, 2011). According to Merriam (2009) not only is the selection criteria of importance, but the reasons for the criteria is also of great importance and needs to be "spelled out".

In this study, four participants were purposively selected based on two selection criteria.

- Participants are parents of children with Down syndrome who are currently enrolled at a mainstream school.
- Participants have completed their formal basic education, which includes primary and secondary school education.

As previously stated the second criteria was deemed as important as this ensures that participants have a full understanding of the research and understood what would be expected of them should they choose to participate in this study. Participants who fulfilled these criteria were seen as information-rich cases (Patton, 2002) that contained the typical attributes required to serve the purpose of the study (Strydom & Delport, 2011).

3.3 DATA COLLECTION

The following section describes the data collection methods used and how the data was analyzed. The researcher made use of the literature review, semi-structured interviews, fieldnotes, and reflective essay questions as modes of data collection and analysis of the data through thematic content analysis.

3.3.1 Literature review

Within any study, the literature review fulfills many purposes (Creswell, 2014). It generally provides a knowledge base, or theoretical framework, placing the current study within a given context (Merriam, 2009). Creswell (2014) states that a literature review provides the platform for the researcher to establish the importance of the current study. In addition to this Creswell (2014) notes that it also provides a basis for the study to compare its results with other findings (Merriam, 2009). Merriam (2009) states that the literature review often integrates the development of the problem statement within a study.

For the purposes of this study, the researcher conducted a literature review to generate a knowledge base, or conceptual framework, as a backdrop for the reader to understand the given study within its context. It also served as a platform for the researcher to compare her findings to the current knowledge base.

3.3.2 Semi-structured interviews

Babbie (2010, p. 381) defines a qualitative interview as an “interaction between an interviewer and a respondent in which the interviewer has a general plan of inquiry”. For the purpose of this study, the researcher chose semi-structured interviews as the primary mode of data collection (Merriam, 2009). This gave the researcher some flexibility during the interviews allowing the researcher to explore new avenues as they emerged during the process (Greef, 2011). An interview guide (refer to Appendix C) was developed, and approved, consisting of the avenues the researcher wished to explore based on the knowledge gained by conducting the literature review. The purpose of the interview guide was to “increase the comprehensiveness of the data” (Patton, 2002, p. 349) gathered. Each interview was between 45 to 60 minutes, except

for one interview which took 1hour and 30 minutes because there was a need to probe for the participants experiences more deeply.

Due to the COVID-19 pandemic and social distancing protocols, interviews could not take place in person. Thus interviews were conducted online via Zoom due to accessibility,and to ensure both the participants and the researcher's safety. A private meeting was scheduled on Zoom and the link was emailed to the respective participant after the participant gave consent and a time and date were agreed upon. The participant only had to click on the link on the given day and time to join the scheduled meeting.

3.3.3 Fieldnotes

Fieldnotes are seen as a rich descriptive tool in qualitative research capturing those elements that cannot be recorded (Given, 2008). According to Greef (2011, p. 359), fieldnotes are a "written account of the things the researcher hears, sees, experiences and thinks about in the course of the interviewing". Given (2008, p. 341) states that fieldnotes "form the context and quality control that shape multiple qualitative data points". During each interview, the researcher made notes, and following each interview, the researcher wrote an in-depth account of the interview. The purposes of these fieldnotes were to remind the researcher of the important elements that merged during the interviews and served as a backup if something went wrong with the recording (Patton, 2002). It also served to facilitate the data analysis process after the data was collected (Patton, 2002).

3.3.4 Reflective essay question

As mentioned in Chapter 1, participants were asked to write a reflective essay question (refer to Appendix D) on their experience on the inclusion of their child with Down syndrome within a mainstream school. This strategy was deemed as appropriate as it allowed more insight into parents' experiences and confirmed what they said during the interviews, whilst complying with social distancing protocols due to the COVID – 19 pandemic.

3.3.5 Data analysis

In qualitative research data, collection and analysis occur simultaneously and are seen as emergent and dynamic (Merriam, 2009; Neuman, 2014). According to Neuman (2014), the goal of data analysis in qualitative research is to organize, integrate, and examine details into a coherent picture by identifying broad themes that improve understanding and advance knowledge. This is also emphasised by Creswell (2014) that states that data needs to be aggregated into a small number of themes. For this study, the researcher made use of thematic content analysis as it can be used across epistemologies and research questions. As previously stated Nowell, Norris, White and Moules (2017, p. 2) states that this method is for "identifying, analyzing, organizing, describing and reporting themes found within a data set".

In this study, the researcher made use of three modes of data collection namely interviews, fieldnotes, and reflective essay questions. The interviews were the primary source of data and were transcribed by the researcher to ensure that she was immersed in the data and therefore more likely to generate emergent insights (Patton, 2002). Handwritten fieldnotes were also typed up by the researcher herself. According to Patton (2002) transcribing and typing up fieldnotes are both points of transition between data collection and analysis and forms apart of data management and preparation.

Data analysis (refer to Appendix E, F, and G) occurred in two phases in this study. In the first phase, the researcher applied an open coding strategy in which she assigned initial codes and themes to the interview transcripts, and reflective essay questions in an attempt to condense the raw data into preliminary categories (Patton, 2002). During the second phase, the researcher applied an axial coding strategy in which she took the initial codes and themes and linked them into broader analytical categories. During this phase of coding the objective is to categorise concepts that cluster together. According to Patton (2002, pp. 483-484), the following questions need to be asked by the researcher:

> *"Can I divide existing concepts into subdimensions or subcategories? Can I combine several closely related concepts into one more general construct?*

Can I organize categories into a sequence, or by their physical location, or their relationship to a major topic of interest?"

The analysis of the emerging themes is discussed in Chapter 4 of this study.

3.4 TRUSTWORTHINESS

Within qualitative research validity and reliability are seen by some as inappropriate constructs not able to establish the truth value as they are quantitative constructs (Schurink, Fouchè, & De Vos, 2011). However, credibility, transferability, dependability, and conformability are all constructs used in qualitative research to increase trustworthiness and thus ensuring validity and reliability (Given, 2008).

3.4.1 Credibility

Credibility refers to the correctness of the researcher's interpretation and representation of the research participants' views (Schurink, Fouchè, & De Vos, 2011). Credibility was ensured by doing a literature review on all the relevant research internationally as well as nationally making use of peer-reviewed scholarly journal articles. Furthermore, the researcher made use of different modes of data collection namely: interview transcripts, fieldnotes, and reflective essay questions.

3.4.2 Transferability

Transferability refers to the degree that the findings of the research can be transferred to another case or situation (Schurink, Fouchè, & De Vos, 2011). Within the study, the transferability of the findings is moderate as some of the findings are supported by the literature, however other findings did emerge that are not supported by the current literature.

3.4.3 Dependability

Dependability asks whether the research process is "logical, well documented and audited" and can be seen as an alternative to reliability (Schurink, Fouchè, & De Vos, 2011, p. 420). Thus within this construct, the focus is for the readers to concur with the researcher that based on the data collected the findings make sense (Merriam, 2009).

3.4.4 Conformability

Conformability captures the concept of objectivity (Schurink, Fouchè, & De Vos, 2011, p. 421). Within this construct, it is important that the research findings can be confirmed by another (Schurink, Fouchè, & De Vos, 2011). As previously stated some of the findings are supported by other researchers, thus removing some of the researcher's subjectivity.

3.4.5 Data verification strategies

Triangulation, audit trail, and researchers reflexivity were all strategies used by the researcher to ensure validity.

3.4.5.1 Triangulation

Merriam (2009, p. 229) refers to triangulation as using "multiple investigators, sources of data, or data collection methods to confirm emerging findings". The researcher made used of three different modes of data collection namely: semi-structured interviews, fieldnotes and reflective essay questions, and multiple sources of data to ensure triangulation.

3.4.5.2 Audit trail

As previously stated an audit trail refers to the detailed account of how a study was conducted (Merriam, 2009). It entails a detailed description of the methodology and how data was analysed, which has been described in great detail in Chapter 3 and Chapter 4 of this study.

3.4.5.3 Researcher's reflexivity

Within qualitative research, the researcher needs to explain his/her "biases, dispositions, and assumptions" of the undertaken study (Merriam, 2009, p. 219). Based on my experience working in a mainstream school that is inclusive of children with Down syndrome, I do believe that the overall experience for the parents has been positive, however, I do believe that there are challenges that the parents and pupils face. Thus, my goal was to highlight these aspects and to identify the challenges that parents and pupils face.

3.5 ETHICAL CONSIDERATIONS

To gain ethical clearance the researcher first compiled a research proposal and all the relevant documents required by the University of Stellenbosch's Ethics Committee for Human Studies. After the submission and several changes, ethical clearance was granted by the University of Stellenbosch's Ethics Committee for Human Studies to the researcher (see Appendix A). Due to the nature of the study, the Ethics Committee recommended that a counselor be made available to participants should they experience any emotional distress which the researcher made provision for. Then only did the researcher contact prospective participants telephonically to invite them to participate in the study. Participants who were willing were then emailed a consent form and after providing consent they were interviewed.

3.5.1 Informed Consent

Informed consent is seen as one of the principles that are deemed necessary in ethical decision making. It acknowledges the participants' own right to choose for themselves (Strydom, 2011). In this study, the participants were contacted telephonically and invited to participate. During this phone call, the researcher explained the purpose of the study, what will be expected of them as participants, and the procedures that will take place should they wish to participate in the study. Participants who were willing to take part then received via email a consent form (see Appendix B) for them to read and sign should they choose to participate. Due to the COVID-19 pandemic, the researcher could not drop and collect the consent forms at prospective participants' houses, therefore participants were asked to sign the forms electronically and email them back to the researcher.

3.5.2 Privacy

According to Strydom (2011) in any given study the attitudes, beliefs, opinions, and experiences need to be protected thus the privacy and identity of each participant need to be ensured. In this study the researcher knew the names of participants and their children, thus to protect their privacy each participant was provided with a code and their children were given a pseudonym during the write-up of the transcripts. These names were then used during data analysis.

3.6 CONCLUSION

This chapter aimed at providing the reader with the methodological outline that was followed in this study. These include the research paradigm, research design and the processes followed for data collection. It also explains in-depth how data were analysed and what ethical considerations were taken during the course of this study. The following chapter will portray the findings and discuss them through the lens of the current discourse.

CHAPTER 4

DISCUSSION AND PRESENTATION OF FINDINGS

4.1 INTRODUCTION

The purpose of this study was to gain a deeper understanding of parents' experiences on the inclusion of their child with Down syndrome in a mainstream school. This chapter discusses and represents the emerging themes that were identified through thematic content analysis.

4.2 RESEARCH PARTICIPANTS

As stated in section 3.2.6 purposive sampling was used to identify potential participants for this study. The four participants, all mothers, who took part in this study have children with Down syndrome who were enrolled in a mainstream school and thus were seen as rich sources of information. Due to the COVID-19 pandemic, interviews and reflective essays were all done via an online platform to maintain social distancing protocols. To protect the identity of participants, their children, and the institutions, codes and pseudonyms were used. Table 4.1 below presents some demographic information of participants and their children. In this chapter when data is quoted references such as P1I or P1E was used. This means that the quote was from Participant 1's interview (I) or essay question (E).

Table 4.1: Participants demographic information

Participants	Parent	Child's age	Child's gender	Inclusive schools attended
Participant 1	Mother	10	Female	Little ABC* and Big ABC*
Participant 2	Mother	8	Female	Little ABC* and Big ABC*
Participant 3	Mother	6	Female	Little ABC*
Participant 4	Mother	9	Male	Little ABC* and Big ABC*

4.3 CONTEXT OF THE RESEARCH

It is imperative that the social context in which a study is conducted is understood, as this may alter the meaning and social significance of the study (see section 3.2.4) (Neuman, 2014). Participants in this study are parents of children with Down syndrome who currently attend a mainstream school. The schools that are attended by their children are Little ABC* and or Big ABC*. Both of these schools are registered private schools within the Cape metropolitan area. Little ABC* is a small inclusive pre-primary school that caters for twenty percent of learners with Down syndrome, while eighty percent of the learners are learners without diagnosed impairments. The school follows the CAPS curriculum as set out by the Department of Basic Education. Participant 1 was one of the founders of the school after she could not find a pre-primary school in the area they live, and that was able to accommodate her daughter at the time.

> (P1): And we decided if there wasn't an inclusive environment for her, we would create an inclusive environment and I was blessed before I had Amy*. I have two good friends with children with Down syndrome. So a Down syndrome child wasn't a strange thing for me and obviously, you make friends once you have a child with Down syndrome with other parents. So I think we had a small community and these children needed to be taken care of. They needed a place to go to and Sue Buckley's research showed how the Down syndrome children do better in an inclusive environment than outside of it if they're able to be mainstreamed. And as you know not all of them are able to be mainstreamed. So for us, it was literally a see and learn because we didn't know what Amy's* capabilities would be call it IQ or call it functionality? I don't know. (P1I)

Big ABC* is a primary as well as a high school and they follow the Accelerated Christian Education (ACE) curriculum, which allows learners to complete their work at their own pace. It did not start out as an inclusive school but later developed into one. Therefore, some of the participants' children attended both schools.

4.4 THEMES AND CATEGORIES

Data has been analysed by means of thematic content analysis. The data that emerged has been arranged according to themes and has further been categorized

into their respective categories. Table 4.2 represents an overview of the categories, themes, and sub-themes that emerged from data analysis process.

Table 4.2: Themes and categories

Category	Themes	Sub-themes
4.5 Parents perceptions of raising their child with Down-syndrome	4.5.1 My child is normal: parents' perceptions of their child.	4.5.1.1 They are individuals. 4.5.1.2 They have their own unique interests and abilities
	4.5.2 The importance of family life	
4.6 Parents experiences of gaining access to mainstream schooling	4.6.1 Motivation of parents to enroll their child in a mainstream school.	4.6.1.1 Concern that their child isn't able to reach their full potential at a special needs school 4.6.1.2 Emulating typical developing peers
	4.6.2 Gaining access to an inclusive environment was a nightmare!	
4.7 Parents experiences of mainstream schooling	4.7.1 Support structures	4.7.1.1 Physical structures that enhance inclusive learning 4.7.1.2 Availability of facilitators 4.7.1.3 Availability of specialized services
	4.7.2 Positive and helpful teachers	
	4.7.3 Having one's child in mainstream schooling is very expensive	
4.8 Parents perceptions of the benefits related to the inclusion of their child with Down syndrome in a mainstream school	4.8.1 Academic benefits 4.8.2 Developmental benefits 4.8.3 Social and behavioral benefits 4.8.4 A culture of acceptance and tolerance is created 4.8.5 Friendships	

4.5 PARENTS' PERCEPTIONS OF RAISING THEIR CHILD WITH DOWN SYNDROME

4.5.1 My child is normal: parents' perceptions of their child with Down syndrome

4.5.1.1 They are individuals

In society, children with Down syndrome are often viewed as different from the norm. However, all the parents emphasized how 'normal' their children are. Just as most other parents, the participants described their child with Down Syndrome as being more extroverted and open, whilst others described their child as shy, loving, and sensitive. And, like any other neurotypical child, many parents reported that their child can also be moody and disobedient at times. Each child thus had their own unique personality. The following quotes encapsulate the parents' responses.

> P1: She's got a very strong personality. She is not shy at all. I would say I would put her in the extroverted sort of category of child … (P1I)

> P1: She's quite particular. It is so funny, because they tell you when you pregnant with a child with Down syndrome or older people will say "dis 'n engel kind", an angel child, and these children are from heaven, straight from heaven. Hmm, but it really is not like that, because they are normal, they are normal children. They have moods, they have temper tantrums, they are disobedient, they manipulate, and she is no different. So she does not just love everyone because she is Down syndrome, or hug everyone because she is Down syndrome. There are people she just does not like, and she does not want to play with and there are grownups that she will refuse to hug or to kiss. And then she has other adults that she adores. (P1I)

> P3: Like any child, she always plays the mom and listens to the dad. So, she's very switched on, very in-tuned, very clued-up … (P3I)

> P4: *Hy is 'n liefdevolle seuntjie met 'n klein hartjie* (He is a loving boy with a tiny heart) … (P4I)

4.5.1.2 They have their own unique interests and abilities

It is a well-known fact that children are unique, and their interests and abilities differ greatly. Like their neurotypical developing peers, the participants reported that their children too have different interests and abilities. This is also supported by research which states that children with Down syndrome have their own unique set of talents and abilities (Down Syndrome South Africa, 2013). The following quotes from the participants illustrates that their children have different interests and abilities.

> P4: *Hy sal nie 'n speletjie speel nie. Hy sal nie soos Jan* buite gaan speel nie, hy sal met sy musiek doenig wees of op 'n foon games speel. Hy so bietjie soos 'n groot kind nou.* (He does not play games. He will not go outside to play like Jan* does, he will either be busy with his music or play a game on a phone. He is a bit like a big boy now.) (P4I)

> P2: She loves music, she loves dancing. I actually started the ballet classes ... the first concert she done all the steps. If she forgot a step she would quickly look at her mates next to her, quickly, but she would be on par with – with everybody else. (P2I)

> P1: She did piano up until the end of last year. She wants to start drama now, so that will be the next thing. She swam, she did swimming lessons, and actually swam in a swimming squad with regular kids up until the end of summer, but with COVID and everything else we have not picked up the swimming again. But she is quite competitive, which is not something I expected to see, but she is the most competitive of my three children. (P1I)

4.5.2 The importance of family life

According to Mash and Wolfe (2010, p. 430) "family relations are the earliest and most enduring social relationships that significantly affect a child's competence, resilience, and sense of well-being". Thus, family relationships are seen as vital in the physical, emotional, and social development of children. The participants reported that the relationships between family members were good and strong. From their responses, it is clear that their children are loved and accepted by their family members and that they are seen as active members of the household.

(P1): … but in our house, she is the social currency. So the two other sisters, her older and younger sister … they fight to play with her. (P1I)

(P2): … she's kind of Daddy's girl. So where Pappa goes she wants to go … (P2I)

(P3): … she absolutely adores her brother she follows him around like a little puppy, they get on, they're two peas in a pod, they're inseparable …, and really he understands her, he gets her, he supports her … (P3I)

4.6 PARENTS' EXPERIENCES OF GAINING ACCESS TO MAINSTREAM SCHOOLS

4.6.1 Motivation of parents to enrol their child in a mainstream school

4.6.1.1 Concern that their child will not reach his/her full potential at a special needs school

As mentioned in Chapter 2, the learning difficulties experienced by children with Down syndrome ranges in severity. Some children may experience mild learning difficulties whilst others may experience more severe barriers to learning (Down Syndrome South Africa, 2013). As a result, many children with Down syndrome are placed in special needs schools due to the barriers they experience. The participants in this study acknowledged that their children experienced learning difficulties, however, they expressed that they did not want their child to attend a special needs school because they felt that their children were higher functioning on the Down syndrome spectrum. Therefore, they might not be challenged enough and given opportunities to demonstrate their abilities. For example, one parent stated: "I would ask the teacher how she is doing. Is she doing okay with her schoolwork? Is she coping? And they said, yes, they're very impressed with her and she is usually the first one done in the class and then she goes and helps the others. So, I knew, okay you have reached your potential here, you know … (P2I)". This quote illustrates how this participant's child was not given an opportunity to go beyond the expectations of the class group. The following quote further demonstrates the concern many of the parents shared:

P4: *Ek was bang om hom in 'n special needs skool te sit, dat hulle stop met akademiese goeters. Hy het tien teen een die potensiaal om eendag bietjie te*

> *kan skryf, 'n bietjie te kan lees, met geld te kan werk, en tyd te kan lees miskien. Waar in special needs fokus hulle dalk, die ander kindertjies in sy klas kan dalk net inkleur, so ons kleur nou net in.* (I was afraid of sending him to a special needs school, because they might stop with academic work. He most likely has the potential to one day write a bit, read a little, work with money and maybe be able to read time. Where in a special needs school the focus might be on the other children in his class who are able to colour in, so then everyone just colours in). (P4I)

It was evident in the data that the participants experienced that special needs schools had lower expectations of their children than mainstream schools. They ascribed this as one of the main reasons why they were motivated to have their child attend an inclusive mainstream school. The following quote describes how all of the participants felt:

> (P1): ... Where she is now, it's extremely strict and there are rules, and particularly the class teacher that she has now, is strict and has a very high expectation of her. And my belief that is that the high expectation that the teacher has of her, is the expectation that Amy* works to meet. Where if there was a lower expectation that would be the expectation she would work to meet. (P1I)

4.6.1.2 Emulating typically developing peers

A strong theme that emerged is that children with Down syndrome emulate what they see. Several participants shared experiences where they witnessed either their own child or other children with Down syndrome mimicking the behaviours of children with special needs. For example, one participant stated: "I saw a Down syndrome child that befriended a CP child who couldn't walk but was dragging himself across the floor. And that was his way of moving, and the Down syndrome child started emulating that and was also dragging himself across the floor instead of walking (P1I)". The fear that their children would emulate behaviours like this was a huge concern for the parents. Instead, they wanted their children to emulate the behaviours of their neurotypical developing peers to bring out the best in them. This is evident in the following quotes:

> (P1) I wanted her to emulate a high-functioning child. And not another child with a different disability and I felt that she had best chance to be the best Amy* that

she could be in that kind of environment. I wanted to try and pull out the best that I could, so to an extent it's pushing her. (P1I)

(P2): So if you put her in a class with typical kids she's going to want to do exactly what they do. That was the important thing for me and I could not keep her in a special needs because she would copy those behaviour ... (P2I)

(P3) ... I wanted her to be with typical children of her own age where she behaves like a typical child … because I can see how; we go camping for a weekend and we're with the family with babies and it's so messy and she comes home and she's sucking her thumb and talking like a baby or wants to wear a nappy. Whereas she's coming home from school now and she's trying to do cartwheels and singing and being like a five-year-old singing in front of the TV with a microphone and acting like a typical child. Cause you know they copy everything. (P3I)

(P4) *... met die Downsies hulle probeer heeltyd wees soos iemand anders. So as jy kindertjies om hom het wat beter is, vinniger hardloop, vinniger iets doen, beter iets doen, mooier praat of whatever. Hulle poog heeltyd om so te wees.* (… Downsies always tries to be like someone else. So if you have children around him who are better, run faster, do something faster, better at something, talks better, or whatever. They will aim to be like that all the time.) (P4I)

4.6.2 Gaining access to an inclusive environment

Although research has established that children with Down syndrome in inclusive environments excel more than their counterparts who attend special needs schools (Buckley et al., 2006; Engelbrecht et al., 2001; Hughes, 2006; Laws et al., 2000; Lorenz, 1999), the participants in this study shared the difficulties that they experienced in gaining access to inclusive mainstream schools. They shared how they approached numerous schools, public and private. However, many of the schools they approached simply stated that they do not accept children with Down syndrome. Thus, they had to search high and low to find a school for their child. Participant 1 stated that she even considered moving to another suburb so that her daughter could be a part of an inclusive school that accepted children with Down syndrome. Parents shared that they felt that some of the schools were not willing to try or even take a chance. One parent

stated that it felt to her that they did not *want* her child. The following quotes illustrate how difficult it was for parents to access an inclusive environment for their child:

> (P1): … I went to all the nursery schools in the area and it sounds terrible, but none of them, none of them were prepared to take her. The mainstream nursery schools and understandably, it was, it's an unknown thing, and I went to the primary school in the area that we live in and the principal made it very clear that even though by law, he is required to take her in … It would be uncomfortable … So we definitely got the feeling that in terms of the mainstream that was there in our area it would be very very difficult … So we looked high and low to find a place that she would thrive in, in fact, we even considered moving to the Southern suburbs, so she could be a part of the school that was already there. (P1I)

> (P4): … *Toe het ek twee skooltjies genader in ons area. Die een het net vir my gesê, hulle vat nie Downs nie, hulle vat net FAS en dan gewone kinders. Die ander skool het gesê, hulle sal hom vat, maar hy moet 'n fasiliteerder hê en dan sal hulle ook vir my na 'n maand of twee of so sê of hy daar mag bly of nie, en of dit sal werk of nie … omdat die ander skool hom in any case nie wou gehad het nie of dis hoe dit vir my gevoel het. Dit het gevoel, hulle wou nie eers probeer het nie; kans gee nie … En toe het ek weer begin rond soek en al die skole gebel, en al wat 'n mens is met 'n Down sindroom konneksie gevra het, wat se skole, maar hoofstroom.* (... Then I approached two schools in our area. The one just told me, they do not take Downs, they only take FAS and then regular kids. The other school said they would take him, but he should have a facilitator and then they would also tell me after a month or two or so whether he may stay there or not, and whether it will work or not … because the other schools did not want him in any case or that's how it felt to me. It felt like they did not even want to try; or give it a chance… And then I started looking around again and called all the schools, and asked everyone with a Down syndrome connection, what's schools but mainstream.) (P4I)

> (P4) *Toe ek vir hom by ons naaste laerskool wou ... ek wou net met die hoof gaan praat het, die kind saamvat en hom gaan vertel wie ons is en wat ons en waar ons vandaan kom, en wat ek van die skool verwag. En ek moes spesifiek in my email vir die sekretaresse skryf :"Moennie vir my sê nee nie, ek wil eers met die*

hoof kom praat, dan kan ons besluit of hy na die skool toe kan kom of nie", maar ek moes dit so uitstipuleer dat ek wil met hom gaan praat. (When I wanted him at our nearest primary school ... I just wanted to talk to the principal, take the child with me and tell him who we are and what we are and where we come from, and what I expect of the school. And I had to write specifically in my email to the secretary: "Do not tell me no, I want to come to talk to the principal first, then we can decide whether he can come to school or not", but I had to stipulate it like that, that I want to come and talk to him first.) (P4I)

4.7 PARENTS' EXPERIENCES OF MAINSTREAM SCHOOLS

4.7.1 Support structures

4.7.1.1 Physical structures that enhance inclusive learning

Little ABC* is a private inclusive pre-primary school established in 2012 that works on an 80/20 percent ratio with a maximum of fifteen pupils per class. Eighty percent of their learners are mainstream learners and the other twenty percent are learners with Down syndrome. Each class has a qualified teacher and an assistant. The assistant's role is to assist the learners with Down syndrome with activities that they might be struggling with. All leaners followed the same curriculum, thus the learners with Down syndrome did exactly what their peers were doing in class, with a little more assistance. Participant 1 stated it as follows:

(P1): So that was really great in terms of Little ABC* in that the inclusivity was on an 80/20 basis. Every classroom had a teacher and an assistant. The assistant was very much in the role of facilitating the child with Down Syndrome, but the idea wasn't to have the Down syndrome child do something separate from the normal class but to be involved in and participate in exactly what everyone else was doing. Or be it at a slightly slower pace or perhaps it was repeated again, but they weren't doing a different curriculum at all. (P1I)

(P4): *So Little ABC* was hy heeltemal deel van die klassie …* (So in Little ABC* he was completely a part of the class …) (P4I)

Children with Down syndrome's verbal capabilities differ greatly. Some are extremely verbal, whilst others are non-verbal. Children with Down syndrome who are non-verbal can learn sign language and it is often seen as a way into language development for them. Teachers and assistants from Little ABC* went on signing courses to learn how to communicate with the children who were non-verbal, thus creating a more supportive environment for the children. Participant 1 stated that one of the pupils who attended Little ABC* in 2012 was, and still is, non-verbal, however, she is very quick and able to communicate effectively with sign language.

> (P1): And it's an amazing school, in the sense that the teachers all went on sign language courses because one of our children that had Down syndrome in the school is still nonverbal. She has minimal verbal capacity, but she's very quick with sign language, able to communicate very efficiently that way. (P1I)

In addition to this, the school has a Diamond programme or otherwise known as a Sunshine room. The purpose of this programme was to identify developmental milestones that each child was struggling with. They were then taken aside for 10 to 15 minutes per day and extra support was provided to assist learners in overcoming these difficulties.

> (P1): And then there was something that we called the sunshine room where we had a specialized teacher that had a special interest in remedial take the child into the sunshine room for a certain period per day and would work on those areas that the child was battling with. (P1I)

> (P4): *... en dan het hulle mos die diamond program gehad, waar hulle die Downsies net bietjie uitgevat het vir 'n rukkie en met hulle afsonderlik gewerk het* (… and then they had the diamond program, where they just took the Downsies out for a while and worked with them separately). (P4I)

Big ABC* is a registered private school that is inclusive of children with Down syndrome, however, it did not start out that way. Participant 1 states it as follows:

> "So Amy* and Kate*, were pioneers in terms of being the first two Down syndrome children to go to Big ABC*, which is now an inclusive school, but wasn't before they arrived in the sense that they'd never had a child with Down Syndrome

> before. So as you can imagine, it does take, I wouldn't say convincing, but it is a different mindset, it is definitely a different way of thinking in terms of accepting a child whose needs are maybe not as well understood or that are different from a neurotypical child, but Ruth* the principal had taken in children on the autistic spectrum and had taken children with physical disabilities. So it was a huge blessing when she accepted the children with Down syndrome to her school." (P1I)

The school set up is different to a conventional school as they have learning centers, instead of grade-specific classrooms, and pupils work at their own pace through workbooks. According to the participants, this unique approach makes it easier to integrate children with Down syndrome into mainstream education whilst allowing them to receive a quality education.

> (P1): They work in paces which is really great because each child can work at their own pace which would suit a child with Down syndrome very well. (P1I)

> (P2): ... But at her rate, she's doing exceptionally well, but- so what they'll do is they'll continue- they'll continue working at her pace. And whatever she needs to complete she will complete at her pace. (P2I)

Participant 4 stated that her son is still busy with grade one work, but due to the physical arrangement of the school, he does not feel that he is progressing at a slower rate than his neurotypical developing peers.

> (P4): *Nee, hulle werk op hulle eie pas, want hy is nou 2 jaar lank besig met graad een en hy gaan nogsteeds met graad een aan. Maar, ek dink nie dit voel vir die kind asof hy agter is nie. Hy voel nie uit of iets nie. Toevallig verlede jaar se groepie het vinnig aanbeweeg, maar hierdie jaar se gropeie het redelik stadig opbeweeg. So amper sy hele klassie gaan volgende jaar aan. Daars net een dogterjie wat aangaan na graad 2 toe. So ja, hulle beweeg op hul eie pas maar hulle doen ook saam goeters.* (No, they work at their own pace, because he has been doing grade one for 2 years now and he is still going on with grade one. But, I do not think it feels to the child as if he is behind. He does not feel out or anything. Coincidentally, last year's group moved on quickly, but this year's groups moved up quite slowly. So almost his entire class goes on next year.

There's only one girl who goes on to grade 2. So yes, they move at their own pace but they also do stuff together.) (P4I)

4.7.1.2 Availability of facilitators in the classroom

Both schools rely on teaching facilitators or assistants. The purpose of a facilitator is to assist learners with the work that they are struggling with and to give them that extra bit of attention that they require. Little ABC* has their own full-time assistants or facilitators and the service costs of these individuals, forms part of the school fees. However, Big ABC* also have their own facilitators, but the service cost is for parents own account. However, to lighten the financial burden, parents of children with Down syndrome at Big ABC* who are in the same class or learning centre, share the cost of the facilitator.

(P3): Yes, so there was an assistant in the class so if they were- the activity for the day… Sorry, if the activity for the day was learning to hold a pair of scissors, cut out a shape um, you know, the typical children were able to do that relatively easy or maybe not so much. But then the Downies were struggling and the facilitator will then sit next to them and assist them, you know, step by step on how to hold a pair of scissors, how to cut until they were able to grasp the concept. And obviously, that was very repetitive, and when she- when she finally learned how to cut and how to use a pair of scissors it was an exciting moment and the facilitator or the teacher would send me a message or a video or share that news with me when I came to pick her up. So there was a lot of one-on-one support and … Which is the advantage of that facilitator and also the advantage of having a smaller class that you get a lot more individual attention so you're not necessarily falling too far behind our typical kids, because of that facilitator you know. And if she is falling behind she'd have that little bit of extra time. (P3I)

(P1): They also have a facilitator or they insist on a facilitator for the children with Down syndrome. So there definitely is that help. (P1I)

(P2): Rose*, so Rose* sits with her and – and the other Downey Henk*. Uhm, so the teacher would obviously give the lesson for the day and at the – I think when they need to do activities then Rose* will assist or her tutor will assist her … (P2I)

(P4): *En by Big ABC* is dit min/meer dieselfde. Hulle is heeltemal in die klassie geïntegreer, die fasiliteerder is daar. Sy gee nou die ekstra ondersteuning, want met die extra herhaling van alles en daai tipe goedjies.* (And with Big ABC * it's more or less the same. They are completely integrated into the class, the facilitator is there. She now gives the extra support, because with the extra repetition of everything and that type of stuff.) (P4I)

4.7.1.3 Availability of specialized services

Both schools make provision for on-site physiotherapists, occupational therapists, and speech therapists to assist parents, especially full-time employed parents, who are not always able to drive around and take their children to the individual therapies. All the participants' felt that this service was extremely helpful, saving them time and effort.

(P1): So we also had some speech therapists would come to the school. We had a physiotherapist that came to the school. We have an occupational therapist that comes to school … And Amy* still sees her OT on a weekly basis at the school. So they make provision for that which is really awesome. (P1I)

(P3): So obviously they offered or they had an on-site speech therapist and OT and uh- if the school felt that Stacey* … felt it necessary for Stacey* to see the speech and the OT; that was made available at school to save me, you know, from running around the countryside to take her to therapies. Which is very very useful, so we made use of that … (P3I)

(P4): *En dan moes ons ons eie arbeids, spraak, fisio gehad het, maar dink arbeids en spraak was by die skool aangebied. Privaat, maar die persoon het in skooltyd gekom.* (And then we had our own OT, speech, physio, but think OT and speech were offered at school. Private, but the person came in school time.) (P4I)

4.7.2 Positive and helpful teachers

In this study, the participants all felt that the teachers had a positive attitude towards their children, and thus had a positive attitude towards inclusion. One parent stated it as follows: "One thing I must say is that the teachers really have compassion for the kids. They're really there for their best interest, you know, for the kids" (P2I). The parents shared how teachers would communicate with them and how they would

celebrate with them when one of the children reached a milestone. The following quotes demonstrate how the participants experienced the teachers' commitment towards their children.

> (P2): Yes, they discipline which is great stuff because Mommy disciplines at home and then teacher disciplines at school … Communication amongst the parents-teachers, all right. I was always informed about my child's progress, which is perfect, which is good. If there was any concern I was notified, you know. (P2I)

> (P3): And then obviously just taking her aside and spending extra time with her. Grace* was very good I had a very good relationship with Grace* that if Stacey* did something extra-ordinary at school that day where it be threading – threading a couple of extra beads or recognising a shade or learning a new colour, she would be very excited and send me a video or a WhatsApp and celebrate those milestones with me which is very rewarding for my husband and I because then we could see developments, we could see this was what we were wanting. Um, and obviously if she regressed in a certain area or highlighted areas we need to work on so they were very proactive, um in that regard. Um, yes and gave us tips and advice, things we could do at home to try and keep her – reach her milestones or keep her on the – on the right sort of path. (P3I)

> (P4): *Ja, ek voel hulle gee baie goeie aandag, aan hom spesifiek. Selfs deur sy juffrou ook, buiten die fasiliteerder, voel ek nie hy word afgeskeep of iets nie. Waar ek wel glo dat hy in 'n hoofstroom skool dalk sou net gefloat het (in 'n groter skool).* (Yes, I feel they pay very good attention, to him specifically. Even by his teacher too, apart from the facilitator, I do not feel he is neglected or anything. Where I do believe he might have just floated in a mainstream school (in a bigger school.) (P4I)

One of the parents mentioned that her child was struggling to learn how to read and how his teacher has adapted and tried different techniques to assist him with reading. She stated the following:

> (P4): *… so hoe dit vir my voel is, hulle probeer verskillende tegnieke om die beste uit hom uit te bring.* (… so how it feels to me, they try different techniques to get the best out of him.) (P4I)

It is clear from the participants' responses that teachers who are positive and helpful towards their children play an important role on their own experiences of inclusive education.

4.7.3 Having one's child in mainstream schooling is very expensive

One of the major themes that emerged from the data was the financial cost of having ones child in an inclusive environment. Parents shared that the financial burden of inclusion was one of the major challenges that they experienced. They shared that as parents they have to pay school fees, the facilitator, all the individual therapies and extra-mural activities if their children participated in them. One parent stated that her child's monthly fees would exceed R10000 if she had to pay for all the services herself. However, as previously stated Big ABC* allows parents to share a facilitator, if their children are in the same class, to decrease the financial burden on parents. The following quotes illustrate how parents felt.

> (P4): *Ja, definitief, want soos hy moet nou in 'n privaat skool wees basies om hom te kan hoofstroom. As ek hom byvoorbeeld in 'n staatsskool wil insit, wat vir my bekostigbaar is, dan moet ek 'n fasiliteerder by stuur wat ses en half duisend rand kos 'n maand. So sy skoolgeld kos baie naby aan R10000 'n maand as ek alles self vir my eie rekening het ... Kyk my situasie hoekom ek moet hoofstroom is hier is nie special needs fasiliteite ook eers nie. So jy het nie die keuse eintlik nie. En tweedens kan ek kom nie in 'n gewone skool sit soos Jan* nie en miskien bietjie vrywaarding van skoolfondse, omdat ek 'n enkel ouer is nie. Daar is nie so iets beskikbaar nie. So hy moet privaat skool toe gaan, waar hy nou eintlik ook 'n fasiliteerder het en moet hê plus al daai terapieë. In my geval probeer ek nog elke jaar dit van die mediesefonds afkry wat help. En deesdae, as jy jou kind in sport wil laat deelneem, Downsies floreer gewoontlik in iets, sê nou maar hy sal goed wees in 'n musiek instrument, of in 'n tipe sport, maar wat jy ook maar privaat moet gaan doen, so dit kos ook 'n klomp geld om die beste uit hom uit te kry. Weet om sy potensiaal te laat bereik.* (Yes, definitely, because like he has to be in a private school now basically to be able to mainstream him. If, for example, I want to put him in a public school, which is affordable for me, then I have to send in a facilitator who costs six and a half thousand rand a month. So his school fees cost very close to R10000 a month if I have everything myself for my own account

> ... Look in my situation why I have to mainstream is there are no special needs facilities either. So you do not actually have the choice. And secondly, I can not put him in a regular school like Jan* and maybe get a little exemption from school fees, because I am a single parent. There is no such thing available. So he has to go to a private school, where he actually also has a facilitator and must have plus all those therapies. In my case, I still try to get it off the medical aid every year that helps. And nowadays, if you want to get your child involved in sports, Downsies usually thrive in something, say he will be good in a musical instrument, or in a type of sport, you have to do privately, so it also costs a lot of money to get the best out of him. Know to reach his full potential.) (P4I)

> (P3): Oh, so it was for our own account um, special needs children are very very expensive. The bills can be- can be very costly. Uh, especially on top of the medical side of medicines and things like that. So the speech, OT, and physiotherapy were for our own account every month. Thankfully we ended up dropping off the physio uh, I can't remember at what age ... I think she was about three or four, as we felt she didn't need it as much and you know we made sure she did trampolining or bean-bag or swimming, that sort of thing. Uh, yes, so she still does speech as her speech needs extra support. We also put the OT aside just for financial reasons last year but I'm certainly gonna look at it again for next year. (P3I)

Another aspect that emerged was that parents felt that if they were able to enrol their child in a mainstream school, with a similar system, closer to where they live it would significantly impact the cost of mainstreaming their child.

> (P2): …if I could have Faith* at a school in Paris* with a similar system. I would gladly have done it because it's close to home. I am almost sure that the school fees would be a little bit cheaper. I think that is my most or my major challenge is the school fees. It's – it is quite high. I understand it's a private school and – and you get quality training but not all parents will be able to afford it – (P2I)

> (P4): *... Dis die ander ding waarvoor ons betaal, dis vervoer al die pad Geelbos* toe, want dis die eerste en naaste plek wat ons kind aanvaar. So ek voel altyd of jy moet baie arm wees dan sal jou kind seker maar êrens inpas of jy moet skatryk*

wees dan privaat skole en al die terapieë dan werk dit, maar die gewone middelklas mense ons hang hier tussen in. (... It's the other thing we pay for, it's transport all the way to Geelbos*, because it's the first and closest place that accepts our child. So I always feel like you have to be very poor then your child will probably fit in somewhere or you have to be wealthy then private schools and all the therapies then it works, but the ordinary middle class people we hang in between.) (P4I)

Participant 2 shared how other parents with children with Down syndrome would like to send their child to a school like Big ABC*, however the school fees are too high for these parents. Thus it automatically excludes their children from an inclusive environment where they might be able to reach their full potential.

(P2): So – so Faith* before where Faith* was at Elijah*, one of the Downs' mommies ask me, hi how's Faith* doing? Because I would post things, you know, especially the ballet I would post things on Facebook and she would say, what school is Faith* at? I also want to put my child in that school. And when I tell them look, this is the school fees ... they back away because they can't afford it. So – and that is so sad Mia* because, other kids might have the same potential as Faith* – (P2I)

4.8 PARENTS' PERCEPTIONS OF THE BENEFITS RELATED TO THE INCLUSION OF THEIR CHILD WITH DOWN SYNDROME IN A MAINSTREAM SCHOOL

4.8.1 Academic benefit

The academic benefit of inclusion is well documented in research (Buckley & Bird, 1993; Buckley et al., 2006; Laws et al., 2000; Hughes, 2006), and parents in this study reported the same. However, it was clear during the interviews that the academic benefit of inclusion was not a big motivator to enroll their children in a mainstream school. Parents shared that they do not expect their children to excel academically, but if they are able to learn some basic reading, writing, and number skills they would be pleased. The following quote from participant 1 clearly demonstrates this sentiment:

> (P1): Ja, this one makes me a little bit teary, because I didn't realize how well she was able to do. I thought in my mind, if she could just read, she could just recognize the price on something or she could recognize what something said, I would be so pleased. I would be so happy. It would make her life easier. Never in a million years, did I think she would take a book and read it to me! Would answer a comprehension test that she writes herself. Never in a million years did I think that she would be able to do a regular grade one curriculum and pass it. And pass it well. So academically for me, she shocked the lights out! And if she wasn't pushed in way that she is pushed, I don't believe that she would achieve that, because they don't treat her like she is Down syndrome. (P1I)

Similarly, participant 2's daughter started grade one in 2020, and within a few months she was able to sound letters phonetically and recognize numbers, especially when presented with dominoes. For this participant, her daughter demonstrating the most basic amounts of academic progress was significant.

> (P2): … Like I said, the teachers were also impressed with what she can do, she counts. Faith* knows her shapes … say the alphabet. It's a little bit different now, because it's phonetics, cause you know, they have to say the "a" "b" "k". Which she does. She comes home uhm- or whenever, just randomly she would mention a word and then she would say, let's say "Mommy b-b-b for ball," you know. (P2I)

> (P2): … So she loves dominoes. She plays dominoes with Ma, Ma also plays cards with her and then earlier I think a few months ago, just when the – when the kids returned to school, teacher Bianca* ask me; "Mamma, speel julle dominoes met die kind?" So I said, yes, she actually does because they could then, she could identify the numbers in the shape of a domino. She could say that's six, that's five, that's three where the other kids, even the typical kids, they were struggling. (P2I)

4.8.2 Developmental benefit

Participant 3 described her daughter's progress in terms of meeting a developmental milestone, especially since she was only five years old at the time of the interview. She shared how her daughter developed like a typical child, reaching her developmental milestones due to being around typically developing peers.

(P3): My child has flourished and developed like a typical child. She copies all her typical friends in areas of imaginary play, on the playground, in speech, and has the confidence to try new things that often children with Down syndrome are too scared to do due to sensory issues, as she wants to keep up with her peers. (P3E)

4.8.3 Social and behavioural benefit

As stated in Chapter 2, a study done by Buckley et al. (2006), showed that teenagers with Down syndrome who were mainstreamed were socially more mature than teenagers that attended special needs schools. This was a major concern and motivational factor for why parents chose to enrol their children in a mainstream school. The participants all emphasized that they wanted their children's' behaviour to be socially acceptable. The following quotes highlight how the participants felt.

(P4): *Wat positief is om vir Henk* in 'n hoofstroom skool te sit is dat hy "normale" en sosiaal aanvaarbare gedrag aanleer. Down sindroom kinders leer deur na-te-boots. Dus in 'n hoofstroom skool poog Henk* om meer te wees (akademies, sport, en sosiaal).* (What is positive about putting Henk * in a mainstream school is that he learns "normal" and socially acceptable behavior. Down syndrome children learn by mimicking. So in a mainstream school, Henk * strives to be more (academic, sports, and social). (P4E)

(P4): *... maar my grootste vrees vir dit was dat hy ander spesial need kinders se gedrag aanleer. En op hierdie stadium is hy baie, as mens van normaal kan praat, maar sy gedrag is aanvaarbaar vir die samelewing op hierdie stadium. En dis hoe dit moet wees, hy hoef nou nie die wêreld se beste akademikus te wees nie, maar sosiaal aanvaarbaar wees. En hy moet homself net 'n bietjie kan handhaaf. So dis my hoof ding …* (... but my biggest fear of it was that he was going to learn other special need children's behavior. And at this stage he is a lot, if one can speak of normal, but his behavior is acceptable to society at this stage. And that's how it should be, he does not have to be the world's best academic, but be socially acceptable. And he just needs to be able to maintain himself a little bit. So that's my main thing …) (P4I)

Participant 1 stated that, because her daughter is treated like a “normal” child at school, her behavior is socially acceptable.

> (P1): She’s not treated as a special child or a glass child or a sensitive or vulnerable child. When she’s naughty, she’s treated like a naughty child and she’s put in timeout, and when she wears the wrong uniform or when she doesn’t wash her hands or she’s disobedient. She is treated like a normal child and as such, she behaves like a normal child and she toes the line, and she stands in her line, and she waits her turn, and she puts up her hand. And she’s a definite participating member of the class that she’s in, and it’s not tolerated for her to behave inappropriately. (P1I)

4.8.4 A culture of acceptance and tolerance is created

Participants stated that their children felt accepted in their inclusive environment, which fosters a sense of belonging. One parent stated that her daughter felt at home at school and did not feel left out. Participant 3 stated that the biggest advantage of her daughter attending a mainstream school is that her peers accept and understand her.

> (P3): … and I think for me that’s the biggest, biggest advantage of her having been in a mainstream school is that those few children that are in her class understand her, they accepted her and possibly ‘cause it’s a Christian school as well they’re taught to accept children that are slightly different and to love everyone. You know, whereas we go camping with a big group of friends and I think there are 20 kids there and suddenly as the kids have got older now they don’t understand why she’s different and they started excluding her in little things because they just don’t get it. (P3I)

> (P3): You know, she’s so accepted there and she can’t wait to go to school in the mornings and all weekend she’s begging to go to school and holidays she’s begging to go to school. And her eyes open in the morning and the first thing she says is, “school day?” Yes, you’re going to school today. “Yaaay.” So ja, and on a Saturday she goes “school today” and I say no … “Me not happy, no”… So, she loves school, she loves going to school, she loves the people there, she loves the friends, she loves the whole environment. (P3I)

(P2): … My child feels at home there, she doesn't feel left out, she's not labeled, you know. So here in our society, in our area she would be labeled, she would be poked fun at, she probably will be bullied and I wouldn't know because she won't be able to communicate properly with me. (P2I)

One of the benefits that emerged in the data was that neurotypical developing children, who attend an inclusive school tend to be more tolerant and accommodating towards children experiencing barriers to learning, as they are taught to accept others that might look different and not have the same capabilities as they do.

(P1): … And it wasn't from the school that she was in because you will find that a child that's in an inclusive school, a neurotypical child, because there are other children in their school. They're extremely tolerant and extremely accommodating towards a child that isn't quite there, af vlerkies. (P1I)

(P4): *… maar ek weet mos daar was die kindertjies geleer om met almal te speel en almal te aanvaar, en bietjie geduldiger te wees met drukkies wat te hard gegee word en sulke tipe goed. Nou daai probleem het ons nou nie meer nie die kinders is nou half volwasse genoeg dink ek om al klaar weer te weet van die ander Downs kindertjies.* (… but I know the kids were taught to play with everyone and accept everyone, and to be a little more patient with hugs that are given too hard and that kind of stuff. Now we do not have that problem anymore the children are now half mature enough I think to already know about the other Downs children.) (P4I)

4.8.5 Friendships

Friendship was an interesting theme in the sense that participants' experiences had not been the same. Participants 1 and 3 shared how their children are invited for playdates and parties outside of school, whilst participants 2 and 4 stated that although their children do have friends at school they have not been to any playdates outside of school time.

(P1): She's one of three sisters, so she has like a built-in friendship group. And strangely, you know, a mom of a Downsy is always worried that they'll fit in and they'll have friends and that people will play with them. And you know, but in our

house, she is the social currency. So the two other sisters, her older and younger sister. Her older sister being her twin sister, exactly 3 minutes older than her, they fight to play with her. So that's quite nice. So they'll say things like,but you played with her the whole morning, you know, and she's always playing with you and now it's my turn my. She knows it, yeah, so she milks it. (P1I)

(P1): Amy is invited to many parties, Down syndrome children's parties, normal children, or neurotypical children's parties. She's sometimes invited to her sisters' friends' parties. (P1I)

(P1): … because the children in her school are used to her and used to children that look like her. And she's included in games, in play dates, in parties. She's, she's well-loved. (P1I)

(P3): …Whereas at school they understand her, you know and they- they play with her she gets invited for playdates and kids wanna come here and play even though she's still pretty … non-verbal/ verbal, however, you want to describe it. (P3I)

(P4): *Maatjies het hy by die skool, maar ja hy word nie eintlik genooi vir playdates deur sy skoolmaatjies nie. Dis ook partykeer waaroor ek dink, ons het so baie ander vriende met kinders van hulle ouderdom waarmee die kinders heeltyd sosialiseer en so pla dit my nie en dit lyk nie asof dit vir hom pla nie. Ek weet ook nie of die ander kinders playdates reel nie, want daars net vier kinders in die klas. Maar ja, daar is nie 'n bakleiery nie en as ons by die skool kom dan groet almal hom. En almal is happy, van graad een tot matriek.* (Friends he has at school, but yes he is not actually invited for playdates by his schoolmates. It's also sometimes what I think about, we have so many other friends with children of their age that the kids socialize with all the time and so it does not bother me and it does not seem to bother him. I also do not know if the other children arrange playdates because there are only four children in the class. But yes, there is no fighting and when we get to school then everyone greets him. And everyone is happy, from grade one to matric.) (P4I)

(P2): ... We don't know all the parents, we don't see the kids often, Faith* only sees them at school, which means there are no playdates you understand. So

there are no playdates and lockdown probably made it a little bit worse. So – so she just sees her classmates during school time where I think other kids who live close by; they know each other, they can easily see one another. Faith* doesn't have that.

Participant 2 also stated that because they live far away from the school and in a less affluent area, she sometimes felt that she did not want her daughter's classmates to see where they lived. This in turn influenced the opportunities her daughter had for building friendships. Therefore, the school environment played an essential role in providing opportunities for children with Down syndrome to socialise and develop friendships.

(P2): … Hene Mia* we live in South Africa, you know, we live in South Africa where certain areas aren't as affluent as other areas. And not that – that is a problem but sometimes for me personally, I wouldn't want Faith's* classmates to see where we live you know, and that's something that – that I need to maybe work on … If there was an occasion where she has a playdate, I would obviously be open to it, but you know ... but I wouldn't just invite Geelbos* kids to Paris* because I also have to consider they are not familiar with the area. You know what I'm saying? (P2I)

(P2): And the elements. So I wouldn't invite any kid unless it's that side where there's maybe a park or the beach or restaurant or – so I also need to consider the area, you know if I ever have to invite her classmate or so. (P2I)

4.9 CONCLUSION

In this chapter, the emerging themes from participants' interviews and reflective essay questions were identified. These themes will be discussed in Chapter 5 according to the research questions.

CHAPTER 5

CONCLUSION AND FUTURE RECOMMENDATIONS

5.1 INTRODUCTION

The purpose of this study was to gain a deeper understanding on parents' experiences of the inclusion of their child with Down syndrome in a mainstream school. The study was conducted within an interpretive paradigm and a basic qualitative research design was used as the researcher sought to gain understanding on parents' experiences. Data was collected through semi-structured interviews, fieldnotes and a reflective essay question. Thematic content analysis was used to identify emerging themes from the data collected. The participants who participated in this study were all parents of a child with Down syndrome who was enrolled in a mainstream school. The two schools that are represented in this study are both registered independent private schools at the Western Cape Education Department. Little ABC* is an inclusive pre-primary school and follows the CAPS curriculum as set out by the Department of Basic Education, whereas Big ABC* follows the ACE (Accelerated Christian Education) curriculum.

In this chapter, the researcher aims to answer the primary research question and sub-questions. This will be done by offering an interpretation of the findings presented in Chapter four. The findings will be discussed in relation to the literature review and conceptual framework presented in chapter two. Several recommendations are then discussed relating to the inclusion of children with Down syndrome in a mainstream school.

5.2 INTERPRETATION OF THE FINDINGS

The interpretation of the findings will be done by answering the primary research question and sub-questions.

Primary research question

> What are the lived experiences of parents on the inclusion of their child with Down syndrome in a mainstream school?

Sub-questions

1. What were the motivational factors behind their decision to enrol their child in a mainstream school vs a special needs school?
2. What are the challenges that are associated with the inclusion of learners with Down syndrome in a mainstream school?
3. What support was offered by the school for learners with Down syndrome?
4. Has the support offered by the school been adequate? And if not, what are the needs for support?
5. What benefits have been associated with enrolling your child in a mainstream school?

5.2.1 What were the motivational factors behind their decision to enrol their child in a mainstream school?

According to the findings, two factors motivated parents to enrol their child in a mainstream school, namely their concern that their child would not reach their full potential at a special needs school and wanting their child to emulate typically developing peers. It is a known fact that one of the most common tendencies of children with Down syndrome is that they tend to copy or mimic the behaviour of others (Down Syndrome South Africa, 2013). Thus, one of the main reasons why the participants in this study wanted their child to be included in mainstream schooling was that they wanted their child to copy the speech, language and behaviours of their peers (Down Syndrome South Africa, 2013). The parents in this study shared that they wanted their children to emulate a high functioning child, especially when it came to social and behavioural aspects, rather than emulate another child with a disability. One of the participants stated that her child does not need to be the world's best academic, but he has to be socially acceptable, referring to his behaviour in society. Research has established that children with Down syndrome who attend a mainstream school tend to demonstrate social behaviour that is more age appropriate (Buckley et al., 2006), because they emulate what they see others do (Down Syndrome South Africa, 2013).

The other factor that motivated parents to enrol their children in a mainstream school was that they were concerned that their children would not reach their full potential in a special needs school. In South Africa, special needs schools cater for a wide range of children experiencing different disabilities for example Down syndrome, Cerebral Palsy, Intellectual disability, etc. Due to the wide range of children that these schools accommodate it can be assumed that not all children will have the same intellectual capacity and learners who are higher functioning than others might not be stimulated enough within that environment to reach their full potential. All of the participants stated that their children were high functioning compared to other children with Down syndrome, thus they felt that their children had the best chance to reach their full potential in a mainstream school. Studies done by Hodapp et al. (as cited in Starr & Foy, 2006) and Kasari et al. (1999) support this finding stating that parents of children with Down syndrome in their studies reported that they too felt that an inclusive environment is a more ideal enducational environment for their children.

5.2.2 What are the challenges that are associated with the inclusion of learners with Down syndrome in a mainstream school?

The South African Constitution and the South African Schools Act 1996 provides the legal framework, in line with international policies for children with Down syndrome to enter mainstream education. In addition to this, research has established that children with Down syndrome do better in an inclusive environment (Buckley et al., 2006; Engelbrecht et al., 2001; Hughes, 2006; Laws et al., 2000; Lorenz, 1999). However, findings in this study suggest that despite their legal right to basic education and the benefits it holds, gaining access to schools, private and public, was extremely difficult for the participants in this study. This speaks to the many barriers that still need to be overcome within the South African education system before the envisioned dream of inclusive education can be implemented as outlined in Education White Paper 6.

A second challenge revealed by the study was that parents experienced inclusive education as overly expensive and a burden to their financial situations. All the participants in this study were from middle-class households, which means that their household income falls between R86001 and R1,48 million per year (Staff Writer, 2016). Therefore, they were financially stronger that 90% of the country (Staff Writer, 2019). However to mainstream their children effectively they needed to be able to

cover the costs for school fees, a facilitator, all the individual therapies their child needed, as well as extra mural activities. One of the participants stated that accessing inclusive education for her child meant spending approximately R10 000 per month. According to an article published on BusinessTech only 10% of South Africans earn more that R7313 a month (Staff Writer, 2019). This implies that effective mainstream education is only available for high-income households and excludes the vast majority of children with barriers to learning, let alone children with Down syndrome. This finding speaks to the social injustices that continue to plague South Africa as a society, but also the education system where the distribution of resources is unequal (Department of Education, 2001; Eloff & Swart, 2018).

5.2.3 What support was offered by the schools for learners with Down syndrome?

Both of the schools represented in this study are small private inclusive schools with small classrooms. Small classrooms allow for more focussed individual attention. In addition to this, each class has a facilitator to assist the children with Down syndrome with the repetition of the work and the aspects that they are struggling with. In Big ABC* pupils work at their own pace, which suites a child with Down syndrome because their developmental rate is generally slower than their peers, and all of them will experience some form of barrier to learning, although the severity of it will vary (Down Syndrome South Africa, 2013). Both schools allow for on-site specialized therapies which makes it easier for parents to access these services. In this study, participants viewed teachers as helpful, willing to adapt work where necessary, and positive towards their children and inclusion. This contributes to the overall satisfaction of parents with the school choice they have made and is supported by research (Kendall, 2017; Starr & Foy, 2006).

5.2.4 Has the support offered by the schools been adequate? And if not, what are the needs for support?

Participants in this study felt that the support offered by the schools was more than adequate. They stated that they were very happy with the schools and with the level of support that has been provided. The only negative aspect that was raised by the participants was the high monthly cost of fees.

5.2.5 What benefits have been associated with enrolling your child in a mainstream school?

Findings in this study show that children with Down syndrome who attend a mainstream school do benefit academically. This finding is in line with previous research (Buckley et al., 2006; Engelbrecht et al., 2001; Hughes, 2006; Laws et al., 2000; Lorenz, 1999). However, where previous research, for example Lawes et al. (2000), indicated that academic attainments are a result of more exposure and focus placed on literacy and numeracy instruction within a mainstream environment, in this study the parents' expectations of their child's academic attainments were not high. Instead, the parents voiced that if their child was able to even read and write a little bit, or if they managed to gain basic numeracy skills, then they would be more than satisfied. To the participants in this study, gaining basic skills meant that their child would be more likely to have a little bit of an easier life.

Another benefit related to having mainstreamed their child relates to the social and behavioural development of children with Down syndrome. Buckley et al. (2006) determined that teenagers with Down syndrome who attended a mainstream school were more socially mature than teenagers who attended a special needs school. The findings of this study are similar in that the social and behavioural benefit of inclusive education is evident. The participants stated that because their children are treated as *"normal"* and inappropriate behaviours are not tolerated within the school environment, their children act in a more socially acceptable manner.

Although research does show that teenagers who attend a special needs school are more likely to have a special friend because there are peers "like me" (Buckley et al., 2006), the findings in this study show that friendships can still be built within an inclusive environment that extends beyond the boundaries of the school premises. For example, two of the participants shared that their children are invited by their neurotypically developing peers for playdates and birthdays parties however that is not everyone's experience.

Another aspect that emerged from the study was that neurotypical developing peers who attend an inclusive school also benefit from the experience of learning alongside peers with barriers to learning. The findings suggest that because they are exposed to

children who are different from them, they are more tolerant and accepting of other people who are different. This fosters a culture of acceptance and tolerance, creating a system that invites and celebrates difference and diversity which according to Landsberg et al. (2011) forms the basis of inclusion.

5.3 RECOMMENDATIONS

In this study the experiences of four parents who have endeavoured to gain access to inclusive environments for their child with Down syndrome is shared. The findings of this study cannot be generalised; however, it does add to the growing body of literature that supports inclusive education for children with Down syndrome. However, within the South African context, effective mainstreaming is costly for parents. Due to the large socio-economic gap that exists within South Africa, this does imply that effective inclusion is only available to a few who can afford it, leaving the vast majority of parents of children with Down syndrome without the option to mainstream. The researcher therefore recommends that the Department of Basic Education either develop smaller schools that work on a similar basis as Big ABC*, where support services are provided by the department, or make facilitators available to parents at public schools to reduce the financial burden on parents' and make inclusive education for children with Down syndrome more accessible.

5.4 RECOMMENDATIONS FOR FURTHER RESEARCH

The study was conducted in two small private schools within the Western Cape which does not represent most schools in South Africa, it is therefore recommended that future research explore parents' lived experiences on the inclusion of their child with Down syndrome in public schools.

5.5 LIMITATIONS

The researcher set out to capture the lived experiences of parents of children with Down syndrome in a mainstream school to gain a deeper understanding of their experiences. In this study the experiences of parents were extremely positive, it is important to note that this is a small qualitative study and generalisations cannot be made. However, findings in this study do support the growing body of literature on the

inclusion of children with Down syndrome. Another limitation is that all the participants' children attend a small private school in the Western Cape, thus further research on parents' lived experiences of inclusive education within a public school is deemed as necessary.

5.6 CONCLUDING REMARKS

The research aimed at understanding the lived experiences of parents of children with Down syndrome in a mainstream school. This was done using a basic qualitative design and data were collected by means of semi-structured interviews, field notes, and a reflective essay question. The overall experience of the participants, in having their child mainstreamed, has been extremely positive, and they encourage other parents of children with Down syndrome to mainstream their children if at all possible. However, findings suggest that the cost of mainstreaming is expensive, and thus many parents of children with Down syndrome would not be able to mainstream their children within South Africa, unless the Department of Basic Education provides adequate support to parents.

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APPENDIX A:
ETHICAL CLEARANCE FOR THE STUDY FROM THE UNIVERSITY OF STELLENBOSCH

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

TITLE OF THE STUDY: Parental experiences on the inclusion of their child with Down syndrome in a mainstream school.

You are asked to participate in a research study conducted by Liezel de Villiers – van den Eijnde, M.Ed Educational Support, from the Department of Educational Psychology at Stellenbosch University. The results obtained will contribute toward a thesis. You were selected as a possible participant in this study because you are a parent of a child with Down syndrome currently attending a mainstream school.

1. PURPOSE OF THE STUDY

The purpose of this study is to gain a deeper understanding of parents' lived experiences on the inclusion of their child with Down syndrome in a mainstream school, as research in this area is very limited.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

Interview:

If you volunteer to participate in this study, I will interview you about your personal experience of enrolling your child in a mainstream school. The interview will take between 45mins to 1hour, via the online application Zoom at a time that is convenient for you. I will send you a secure link via email or telephonically, depending on your personal preference, with which you will be able to join "the meeting". The interview will be recorded and transcribed afterwards. I will only store the audio recording and the transcription while the visual recording as well as the playback will be immediately deleted after the interview to protect your identity. You will be allowed to read the transcription of the interview afterwards, should you wish to do so.

Reflective question:

If you agree to participate in this study, I will also ask you to write a page/3 paragraphs about your personal experience and whether you would recommend other parents with Down syndrome children to enrol them in a mainstream school. I will ask you to email your responses to me at liezelvandeneijnde@gmail.com.

3. POTENTIAL RISKS AND DISCOMFORTS

If any discomfort is experienced due to the interview, a counselling session will be arranged at Aquila Counselling Services if the need arises. The first counselling session will be paid by the researcher. You have the right not to answer a question if it makes you feel uncomfortable.

Corlia Erwee at Aquila Counselling Services, Blouberg

083 550 1760 or corlia@aquilacs.co.za

4. POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

Research done in this area is very limited. Thus in participating in this study you will contribute by broadening the research done in this field. This thesis and paper will provide other parents with the information they need in order to decide whether to enrol their child in a mainstream school or send them to a special needs school. Also, it aims to identify the challenges that parents and learners face so that they are hopefully addressed in the near future.

5. PAYMENT FOR PARTICIPATION

There will be no payment for participation in this study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Privacy will be maintained through storing voice recordings and transcripts in files, protected by a password, on the researcher's computer. The password will only be known by the researcher and her supervisor. All data collected will be anonymised and pseudonyms will be used in the thesis and any papers published to protect your identity.

After the research process, the findings of the study will be made available to you as parents and participants of this study.

If you wish to have a copy of your recording it will be made available to you.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and remain in the study.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Liezel de Villiers on 074 3086830 or email liezelvandeneijnde@gmail.com alternatively please contact my supervisor Dr Carmalita Jacobs at 021 808 9618 or email carmelitaj32@sun.ac.za.

9. RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights, or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, contact Mrs Malene Fouche (021 808 4222; mfouche@sun.ac.za) at the Unit for Research Development.

10. SIGNING OF CONSENT FORM

If you choose to participate please sign the form and email it back to liezelvandeneijnde@gmail.com or send a voice note via Whatsapp to 0743086830 stating that you have read the consent form and agree to participate in this study.

SIGNATURE OF RESEARCH PARTICIPANT OR LEGAL REPRESENTATIVE

The information above was described to me, _____ by Liezel de Villiers in English and I am in command of this language or it was satisfactorily translated to me. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

_____

Name of Participant

_____ _____

Signature of Participant Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the participant]. [He*/she] was encouraged and given ample time to ask me any questions. This conversation was conducted in English and no translator was used by Liezel de Villiers.

_____ _____

Signature of Investigator Date

APPENDIX B:
INFORM CONSENT FORM PROVIDED TO RESEARCH PARTICIPANTS

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

NOTICE OF APPROVAL

REC: Social, Behavioural and Education Research (SBER) - Initial Application Form

11 September 2020

Project number: 7055

Project Title: PARENTAL EXPERIENCES ON THE INCLUSION OF THEIR CHILD WITH DOWN SYNDROME IN A MAINSTREAM SCHOOL.

Dear Miss Liezel Van Den Eijnde

Your REC: Social, Behavioural and Education Research (SBER) - Initial Application Form submitted on 31 August 2020 was reviewed and approved by the REC: Social, Behavioural and Education Research (REC: SBE).

Please note below expiration date of this approved submission:

Ethics approval period:

Protocol approval date (Humanities)	Protocol expiration date (Humanities)
11 September 2020	10 September 2023

SUSPENSION OF PHYSICAL CONTACT RESEARCH DURING THE COVID-19 PANDEMIC

Due to the Covid-19 pandemic and resulting lockdown measures, all research activities requiring physical contact or being in undue physical proximity to human participants has been suspended by Stellenbosch University. Please refer to a formal statement issued by the REC: SBE on 20 March for more information on this.

This suspension will remain in force until such time as the social distancing requirements are relaxed by the national authorities to such an extent that in-person data collection from participants will be allowed. This will be confirmed by a new statement from the REC: SBE on the university's dedicated Covid-19 webpage.

Until such time online or virtual data collection activities, individual or group interviews conducted via online meeting or web conferencing tools, such as Skype or Microsoft Teams are strongly encouraged in all SU research environments.

If you are required to amend your research methods due to this suspension, please submit an amendment to the REC: SBE as soon as possible. The instructions on how to submit an amendment to the REC can be found on this webpage: [instructions], or you can contact the REC Helpdesk for instructions on how to submit an amendment: applyethics@sun.ac.za.

GENERAL REC COMMENTS PERTAINING TO THIS PROJECT:

INVESTIGATOR RESPONSIBILITIES

Please take note of the General Investigator Responsibilities attached to this letter. You may commence with your research after complying fully with these guidelines.

If the researcher deviates in any way from the proposal approved by the REC: SBE, the researcher must notify the REC of these changes.

Please use your SU project number (7055) on any documents or correspondence with the REC concerning your project.

Please note that the REC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

CONTINUATION OF PROJECTS AFTER REC APPROVAL PERIOD

You are required to submit a progress report to the REC: SBE before the approval period has expired if a continuation of ethics approval is required. The Committee will then consider the continuation of the project for a further year (if necessary).

Once you have completed your research, you are required to submit a final report to the REC: SBE for review.

Included Documents:

Document Type	File Name	Date	Version
Letter of support_counselling	aquila lletter for liezl de villiers	21/03/2020	1
Data collection tool	Reflective essay question	16/08/2020	2
Research Protocol/Proposal	24 April 2020 (1)	30/08/2020	7
Informed Consent Form	consent form 2020(1).edited (1)	30/08/2020	
Data collection tool	Interview guide.edited (1)	30/08/2020	3
Default	Response letter vs 6	30/08/2020	6

If you have any questions or need further help, please contact the REC office at cgraham@sun.ac.za.

Sincerely,

Clarissa Graham

REC Coordinator: Research Ethics Committee: Social, Behavioral and Education Research

National Health Research Ethics Committee (NHREC) registration number: REC-050411-032.
The Research Ethics Committee: Social, Behavioural and Education Research complies with the SA National Health Act No.61 2003 as it pertains to health research. In addition, this committee abides by the ethical norms and principles for research established by the Declaration of Helsinki (2013) and the Department of Health Guidelines for Ethical Research: Principles Structures and Processes (2nd Ed.) 2015. Annually a number of projects may be selected randomly for an external audit.

Principal Investigator Responsibilities

Protection of Human Research Participants

As soon as Research Ethics Committee approval is confirmed by the REC, the principal investigator (PI) is responsible for the following:

Conducting the Research: The PI is responsible for making sure that the research is conducted according to the REC-approved research protocol. The PI is jointly responsible for the conduct of co-investigators and any research staff involved with this research. The PI must ensure that the research is conducted according to the recognised standards of their research field/discipline and according to the principles and standards of ethical research and responsible research conduct.

Participant Enrolment: The PI may not recruit or enrol participants unless the protocol for recruitment is approved by the REC. Recruitment and data collection activities must cease after the expiration date of REC approval. All recruitment materials must be approved by the REC prior to their use.

Informed Consent: The PI is responsible for obtaining and documenting affirmative informed consent using **only** the REC-approved consent documents/process, and for ensuring that no participants are involved in research prior to obtaining their affirmative informed consent. The PI must give all participants copies of the signed informed consent documents, where required. The PI must keep the originals in a secured, REC-approved location for at least five (5) years after the research is complete.

Continuing Review: The REC must review and approve all REC-approved research proposals at intervals appropriate to the degree of risk but not less than once per year. There is **no grace period.** Prior to the date on which the REC approval of the research expires, **it is the PI's responsibility to submit the progress report in a timely fashion to ensure a lapse in REC approval does not occur.** Once REC approval of your research lapses, all research activities must cease, and contact must be made with the REC immediately.

Amendments and Changes: Any planned changes to any aspect of the research (such as research design, procedures, participant population, informed consent document, instruments, surveys or recruiting material, etc.), must be submitted to the REC for review and approval before implementation. Amendments may not be initiated without first obtaining written REC approval. The **only exception** is when it is necessary to eliminate apparent immediate hazards to participants and the REC should be immediately informed of this necessity.

Adverse or Unanticipated Events: Any serious adverse events, participant complaints, and all unanticipated problems that involve risks to participants or others, as well as any research-related injuries, occurring at this institution or at other performance sites must be reported to the REC within **five (5) days** of discovery of the incident. The PI must also report any instances of serious or continuing problems, or non-compliance with the RECs requirements for protecting human research participants.

Research Record Keeping: The PI must keep the following research-related records, at a minimum, in a secure location for a minimum of five years: the REC approved research proposal and all amendments; all informed consent documents; recruiting materials; continuing review reports; adverse or unanticipated events; and all correspondence and approvals from the REC.

Provision of Counselling or emergency support: When a dedicated counsellor or a psychologist provides support to a participant without prior REC review and approval, to the extent permitted by law, such activities will not be recognised as research nor the data used in support of research. Such cases should be indicated in the progress report or final report.

Final reports: When the research is completed (no further participant enrolment, interactions or interventions), the PI must submit a Final Report to the REC to close the study.

On-Site Evaluations, Inspections, or Audits: If the researcher is notified that the research will be reviewed or audited by the sponsor or any other external agency or any internal group, the PI must inform the REC immediately of the impending audit/evaluation.

APPENDIX C:
INTERVIEW GUIDE FOR SEMI-STRUCTURED INTERVIEWS

Interview guide

1. Demographic information

1.1 How old are you? And your wife/partner?

1.2 How old is your child?

1.3 Did you know that you were expecting a baby with Down syndrome?

1.4 Has your child suffered or been diagnosed with any significant health problems after birth? Please elaborate

2. Inclusion

2.1 Motivations for enrolling child into a mainstream school

- Please share with me why you chose to enrol your child in ABC school.
- Were there any other schools that you considered?
    - What made you decide against it
- Did you consider enrolling your child in a special needs school?
    - What made you decide against it?

2.2 Experiences on support provided

- Please share your experiences on the support that the school provides.
- Describe the types of support that school provides.
    - OT, Speech, Learner support, Facilitators, adaption of work.
- Do you feel that the support provided is adequate? Please elaborate.

2.3 Child's needs as it pertains to schooling

- What are the 'types of support'/support structures that you feel your child requires to succeed in an inclusive school?

2.4 Challenges experienced with regards to inclusion

- Tell me about the challenges that you as a parent experience in this inclusive school.
    - Learning/ developmental
    - Friends
    - Bullying
    - Feedback
- Do you feel that your child is an active member of the school? What makes you say so?

APPENDIX D:
REFLECTIVE ESSAY RESEARCH QUESTIONS SENT VIA EMAIL TO PARTICIPANTS

Reflective essay questions:

Q1: In your personal experience, what positive outcomes do you associate with enrolling your child in a mainstream school?

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Q2: What challenges have you experienced in mainstream education?

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Q3: Based on your personal experience, would you recommend that other parents with Down syndrome children enrol them in a mainstream school? Please explain your answer.

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APPENDIX E:
EXAMPLE OF DATA ANALYSIS FROM INTERVIEWS INTO UNITS OF MEANING

Portion of interview with Participant 1

I: Investigator

P1: Participant 1

	Transcript	Codes
22	P1: I did look at other schools. I looked at I think I looked everywhere. I actually chatted to Nursery schools, all the nursery schools in the area. Actually forget this. You asking me about it. Now I'm remembering things that I've actually forgotten. I went all a nursery schools in the area and and it sounds terrible but none of them. None of them were prepared to take her. The mainstream Nursery schools and understandably, it was, it's an unknown thing and I went to the primary school and in the area that we live in and the principal made it very clear that even though by law, He is required to take her in, he would make it uncomfortable. It would be uncomfortable. That's what he said, it would be uncomfortable. He said it would be very uncomfortable. So we definitely got the feeling that in terms of the mainstream that was there in our area it would be very very difficult. And in terms of the special needs schools, we looked at Dolphine College*, we looked at Cheryl Ann* as I said. There is another school Rooibos* that has taken in some Down syndrome children, Pampoenkraal* has taken in some Down syndrome children. So we looked high and low to find a place that she would thrive in, in fact we even	Access to an Inclusive environment

	Transcript	Codes
	considered moving to the Southern suburbs. So she could be apart of the school that was already there.	
23	I: Tell me just quickly when you investigated, for example, Seal College or Chere Botha. What made you decide against not enrolling into a special needs school? If I may ask like that.	
24	P1: I think it's anecdotal, because I don't have hard evidence on this	
25	I: just your experience.	
26	P1: Ja, that which that which I had heard from others, was definitely that children that were able to read before going to some, not inclusive,but some of the special needs schools. That behavior had regressed and at their skills had regressed. And because alot of the special needs schools, say Cheryl Ann* for instance, started as a purely Down syndrome school, but later it had evolved and children with cerebral palsy were admitted and children with all sorts of disabilities were admitted to the school. Hm, obviously because there was a huge need, but for instance one of the examples that I saw was a Down syndrome child that had befriended a CP child, who couldn't walk bit was draging himself across the floor. And that was his way of moving and the child with Down Syndrome had started emulating that and was also dragging himself across the classroom instead of walking because that's what he's best friend was doing. So that was it. That was a huge concern for me. I wanted her to emulate a high-functioning child. And not	IE vs Special needs Copying

	Transcript	Codes
	another child with a different disability and I felt that she had best chance to be the best Amy that she could be in that kind of environment. I wanted to try and pull out the best that I could, so to an extent its pushing her. We weren't relaxed about her development you know. As long as she's happy, we just didn't see it like that. We did push her.	Emulationg neurotypical developing peers

APPENDIX F:
EXAMPLE OF DATA ANALYSIS FROM REFLECTIVE ESSAY QUESTIONS INTO UNITS OF MEANING

Reflective essay question from Participant 3

Question	Feedback	Codes
Q1: In your personal experience, what positive outcomes do you associate with enrolling your child in a mainstream school?	My child has flourished and developed like a typical child. She copies all her typical friends in areas of imaginary play, on the playground, in speech, and has the confidence to try new things that often children with DS are too scared to do due to sensory issues, as she wants to keep up with her peers.	Emulating typical developing peers
Q2: What challenges have you experienced in mainstream education?	No real challenges as yet as she is only 6. We have been happy with everything so far.	
Q3: Based on your personal experience, would you recommend that other parents with Down syndrome children enrol them in a mainstream school? Please explain your answer.	I definitely think it's a good place to start, depending on your child's level of functioning. It's important to raise them like a type child and include them into society as much as possible in order for them to reach their potential. Being around typical children encourages inclusion; they copy their	Benefits of Inclusive Education

Question	Feedback	Codes
	peers which encourages them to reach milestones. The sky is their limit, don't put them in a box just because they have a disability, they are full of surprises!	

APPENDIX G:
EXAMPLE OF DATA ANALYSIS INTO THEMES

Category: Parents experiences of gaining access to mainstream schools	
Theme 1: Motivation of parents to enrol their child in a mainstream school	
Subtheme 1: Concern that their child aren't able to reach their full potential at a special needs school	Subtheme 2: Emulating typical developing peers
P1: And because alot of the special needs schools, say Cheryl Ann* for instance, started as a purely Down syndrome school, but later it had evolved and children with cerebral palsy were admitted and children with all sorts of disabilities were admitted to the school. Hm, obviously because there was a huge need, but for instance one of the examples that I saw was a Down syndrome child that had befriended a CP child, who couldn't walk bit was draging himself across the floor. And that was his way of moving and the child with Down Syndrome had started emulating that and was also dragging himself across the classroom instead of walking because that's what he's best friend was doing.	**P1:** That was a huge concern for me. I wanted her to emulate a high-functioning child. And not another child with a different disability and I felt that she had best chance to be the best Amy that she could be in that kind of environment. I wanted to try and pull out the best that I could, so to an extent its pushing her. We weren't relaxed about her development you know. As long as she's happy, we just didn't see it like that. We did push her.

Theme 2: Gaining access to an inclusive environment was a nightmare
P1: I did look at other schools. I looked at I think I looked everywhere. I actually chatted to Nursery schools, all the nursery schools in the area. Actually forget this. You asking me about it. Now I'm remembering things that I've actually forgotten. I went all a nursery schools in the area and and it sounds terrible but none of them. None of them were prepared to take her. The mainstream Nursery schools and understandably, it was, it's an unknown thing and I went to the primary school and in the area that we live in and the principal made it very clear that even though by law, He is required to take her in, he would make it uncomfortable. It would be uncomfortable. That's what he said, it would be uncomfortable. He said it would be very uncomfortable. So we definitely got the feeling that in terms of the mainstream that was there in our area it would be very very difficult. **P1:** So we looked high and low to find a place that she would thrive in, in fact we even considered moving to the Southern suburbs. So she could be apart of the school that was already there.